# DEVELOPING STAFFED HOUSING FOR PEOPLE WITH MENTAL HANDICAPS

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# 1. Introduction

This book is about achieving a fundamental and lasting improvement in the standard of residential services offered to people with major intellectual disabilities in our society. It is about offering people an ordinary life in the community, no matter how severe their disability, instead of sending them away to institutions.

Although 'community care' has been the goal of people working in long-stay services for over twenty years, most of the new development in this period has either served people with relatively little disablement - people who have been labelled as 'mildly mentally handicapped' or 'recovered' or 'stabilised' psychiatric patients or old people not seen as needing nursing care. Even where they do exist, community-based services have often retained many of the features of the large long-stay hospital, and have excluded people from participating in and controlling all those activities of daily living which make up the richness and variety of 'an ordinary life'.

Throughout this period, people like Peter Townsend have argued for using ordinary housing to re-develop residential services for everyone in long-stay hospitals. This argument has been best developed in mental handicap, where there are now a small number of innovatory services in Britain showing how even very heavily handicapped people can live in ordinary housing with enough staff support. Many more groups of people want to start services designed on this model in areas where service planning has traditionally been concerned with building new types of institution. This book is addressed to these people: it describes the different aspects of a staffed housing service for people with mental handicaps, including people with added physical handicaps or 'behaviour problems'. The assumption behind this book is that the opportunities provided by the staffed housing model can be made available, with enough staff support and creativity, to even the most profoundly

mentally handicapped person, including people it is sometimes suggested 'cannot benefit' from improved quality of care because of their withdrawn, asocial behaviour. Staffed housing in the community at least offers opportunities for better family contact and a more pleasant home environment; with skilled staff support, it offers the opportunity for everyone to participate more in the running of their lives, to grow and develop as individuals. The evidence of good practice elsewhere is that no-one should be written off as beyond help.

The book is not intended to describe a model to be slavishly followed step-by-step. Insofar as there is a 'model' it is a way of thinking through the many decisions that are made as a scheme is put together, decisions which will directly affect the quality of life of the people served when the scheme becomes operational. Copying one scheme exactly is not, in any case, desirable: the content of the scheme (i.e. the result of all those decisions) should improve every time a new scheme is started as more experience and confidence is gained and as the limits imposed by prejudice and ignorance are pushed back.

Nor is this book intended to contribute to the debate about whether housing services can best meet all the needs of people who are mentally handicapped, or whether there might be some continuing need for institutional care. It assumes a commitment to caring for people in ordinary housing, providing as much help as they need to live a full life in the community, rather than writing some people off to institutional care. A great deal of effort has already been spent in arguing this case, both from first principles and from the available research. Perhaps if as much effort can now be spent in trying to develop good quality services based on the housing model, the practical experience gained will prove more effective in winning the confidence and acceptance of sceptics than argument from first principles. It could also bring about a dramatically improved lifestyle for many people who will otherwise be served by hospitals, hostels and other kinds of institution.



## Principles of a Service for People

All services are built round a set of principles that embody values and assumptions about the people being served - about what is and what is not 'worth doing' and what things are taken for granted. Often these principles are obscure and easier to infer from what a service actually does than from lists of worthy, if vague, objectives.

One reason for spending time working out what the principles of a new service development should be is to help resolve the inevitable conflicts and tensions between different goals in the service at the beginning. If inconsistencies are allowed to get through into the new service, they may not only have drawbacks for service users but may also create opportunities to divert or destroy the new initiative. It is therefore important to know what compromises are being made and what issues are not being tackled.

Clarity may also help the people initiating a new project to explain what it is they are trying to achieve - something they will have to do over and over again in the course of developing the service. A coherent statement of principles helps both in the justification of particular decisions and in building a coalition of supporters sympathetic to the proposed scheme.

The central belief about using ordinary housing is that people will be better off integrated into the community. 'Better off' really means two things - that people will have a wider range of choices and opportunities in their life, and that they will have access to better help (because it is at least as good as that available to people without handicaps). The function of the service is to translate these opportunities into reality. Thus, using ordinary housing is not just about physical integration - moving people into the community but not doing anything to build up their relationships with other people - it is about social integration too. Neither should integration be seen as 'making people be normal'; essentially it is about opening up as wide a range of choice as exists for

devalued people. Two evaluation tools - Program Analysis of Service Systems (PASS) and Program Analysis of Service Systems' Implementation of Normalization Goals (PASSING) - have been developed to teach people about the idea and the components and features of services which impinge on the competence and reputation of the people served. In terms of developing services for people with severe and profound mental handicaps, the principle of normalisation challenges service providers to judge what they are doing against the best which can be imagined rather than against the norm for services in the immediate past, and to attend to a wider range of issues than might otherwise be the case.

*The Behavioural Approach*

Constructing services so that they achieve particular results in terms of the lives of the people who use them requires some sort of theory of human behaviour, to suggest the likely effects of one course of action rather than another. Behaviourism, in the form developed by Skinner, offers such a model. It so happens that behavioural psychology has made a particular impact in mental handicap, but behaviourism offers a useful framework with which to view anyone's behaviour.

The primary characteristic of the behavioural approach is that it rejects explanations of behaviour based on unobservable events or states inside the person (like the psychoanalytic constructs). It does not deny that people have experiences which others cannot verify; it simply requires that, in terms of trying to understand human behaviour, the process of linking cause and effect uses only observable events in the person (their biology), in the person's behaviour and in the environment. Thus it provides a kind of Occam's razor, paring down over-complicated explanations to get at what could be seen to happen.

The major relationship between behaviour and the environment is described by the law of reinforcement:



environmental events following a behaviour may increase or decrease the likelihood of it occurring again. By identifying these events (reinforcers) and pairing them with particular behaviours those behaviours can be strengthened or weakened. By patterning the reinforcement in particular schedules, behaviour can be made more or less resistant to change. The power of this relationship between behaviour and its consequences has been widely demonstrated and catalogued in the scientific literature: at the most general level its importance is that it focuses attention on the function served by a particular kind of behaviour - on what impact the behaviour has in terms of the consequences that follow when it occurs.

The other major relationship is between events that precede behaviour and the behaviour itself. These can either exert some cueing or triggering effect, when the individual learns (or discriminates) to use the behaviour only in the presence of certain conditions, or they can be a necessary kind of help (a setting event). Therefore, just as the idea of reinforcement directs attention to what happens in the person's environment after the behaviour occurs, so the ideas of discriminative stimuli and setting events focus on what happens before, and particularly on the kind of information available to the person as to what to do and when, and the kind of help or assistance provided by the environment to enable them to execute the task.

Three benefits follow from using the behavioural paradigm. The first is that it tends to emphasise the search for variables that are manipulable in order to change behaviour. Approaches that identify variables such as early childhood experience or social class as important determinants of behaviour (which they may well be) have the drawback for work with individuals that these things cannot be changed once they have happened. Similarly, generalisations about behaviour like personality or attitude are usually too global in concept to tackle in terms of actually doing anything about them. The behavioural approach looks instead to variables in the immediate

circumstances which generally tend to confirm those beliefs in a self-fulfilling prophecy. For example, if people believe that the elderly are confused and forgetful they may design special homes for old people where every corridor is like every other (to reduce the amount that has to be remembered); by removing the differences between areas, they will increase the chances that old people will get lost in the building, thus confirming that the elderly are confused and forgetful.

This relationship between expectation and outcome can form a 'vicious circle' in which lower expectations result in lower achievement which itself feeds lower expectations. For what Wolfensberger calls 'devalued' people, the expectations drawn on have negative connotations and implications, which are conveyed through the kind of physical environment made available (hospitals for the sick, zoos for the bestial, prisons for the menacing); the activities in which the person can engage (being a 'vegetable' or a 'fool' or a child); the language used about them (a dement, a headbanger, a moron); the kind of people around them ('other' sick people and nurses in a hospital, religious devotees in a voluntary home) and the kind of symbolism or imagery used (childish materials and decorations, posters of animals, staff wearing keys on lanyards). All these features act together to imply or require certain ways of behaving in the people concerned who, as they adapt to these expectations, justify them and encourage their extension.

The idea of normalisation is that this process can be reversed, by consciously disrupting the expectations generated by the devaluing role. By creating and supporting a socially valued role for an individual, the goal is that services create expectations for achievement to which that individual and those around them will respond.

Since a simple and obvious objection to this and other social deviance theories is that it is not possible for people with real disabilities or differences to live up to the level of expectations which the wider society might value, it is important to distinguish the outcome from the means of getting there. Normalisation is not intended to be about



making people aspire to a valued role without help; rather it is about making the most of each person's potential and then constructing around them a web of support and help which enables them to occupy the desired role. Some of this support will be overt, in the form of social services; but most of it will be informal and derived from the individual's access to mainstream opportunities and experiences. In terms of selecting between kinds of help, the principle of normalisation involves recognising that the means used themselves convey expectations and assumptions about the person, so that one current definition is:

> As far as possible, the use of culturally valued means in order to enable, establish and/or maintain valued social roles for people (Wolfensberger and Thomas, 1983)

Just as the idea that normalisation is about making people survive without help is mistaken, so another common misconception is that it is about making people normal, in the sense of requiring conformity or mediocrity. Wolfensberger suggests that the perception of individuals who are at risk of being devalued (either because of the number and/or variety of devalued characteristics or attributes they have or because of those possessed by people they are grouped together with) can be changed either by reducing or ameliorating their deviant characteristics or by outweighing them with other positively-valued characteristics. Thus, although conformity with prevalent social norms may be a useful strategy (what sociologists call 'passing'), another is to disrupt the pattern of negative stereotypes with positively-valued characteristics (as when a man using a wheelchair is discovered to be a father, or a former soldier, or a university professor; or when someone labelled as severely mentally handicapped is discovered to have a real job, or to speak a second language).

Wolfensberger's work, although often misrepresented or misunderstood, has been influential in drawing together different strands of thought about services for

everyone else - not simply changing the one choice ('be different') for one other ('be the same').

There are four sorts of justification for supporting access to a full range of opportunities and life chances for people with disabilities. First, there is simply the argument for social justice - that there is no good reason for not supporting equality of opportunity. Since those who want to deny access usually justify their position by saying that handicapped people get better care or treatment or help in segregated settings, this argument focuses attention on the trade-off - how much do people lose when they go into segregated services, how good are those services at what they claim to do, how could the extra help they claim to offer be provided in the community? The working assumption of proponents of community-based services is that they should accomplish all that has been achieved in segregated services and provide the opportunity to achieve much more.

A second justification is that access to the full range of opportunities and choices directly benefits the individual in terms of their competence - their ability to control their own lives. Help to become involved in more activities and choices contributes to improvement in the skills and abilities the person can master, the breadth of their experience and the number, range and richness of their relationships with other people. Since services are supposed to promote independence they cannot really justify holding people back in a restricted circle of opportunities for individual development.

The third and fourth reasons for enabling people with mental handicaps to live in the community are to do with how people who are handicapped or disabled are seen by everyone else. If an individual has personal social relationships with other people, it is argued, their disabilities are more likely to be seen as only a part of their overall character, and the treatment they receive is likely to be better because they are seen as having many needs in common with other people. The people with whom they have these relationships will be more likely to champion their interests, just as other people can rely on



friends for support in times of difficulty. This argument emphasises the importance of personal relationships between individual members of the minority group (people with mental handicaps) and the people in the majority, in contrast to the segregation which is often provided by traditional services. The fourth argument makes a similar but distinct point: in so far as members of the main social groups in society have in their own experience some relationships with people with mental handicaps, they may be more likely to support the cause of that group when it comes to making decisions about resources or rights. Thus, in addition to any benefit the actual individuals they know might experience, there would be a more general and longer-term benefit for the minority as a group.

### *The Principle of Normalisation*

This focus on the personal relationships between people with mental handicaps and members of the wider community has been most fully explored in the development of the principle of normalisation (sometimes called *social role valorization*) by Wolfensberger. For Wolfensberger, the single primary goal of services "is to create or support socially valued roles for people in their society".

This emphasis on social role reflects Wolfensberger's adoption of a social deviancy model of disability, in which the individual characteristic (whether constitutional or acquired), which is the primary difference between the individual and others (like severe learning difficulty), is seen as overlaid by a secondary set of expectations for the behaviour and characteristics of the individual that reflect commonly-held views about 'this sort of person' (like childishness or clumsiness). The usefulness of this approach is that it directs attention to the effect of these expectations on the actual outcome for the person labelled as different - to the extent to which beliefs about people with some noticeable characteristic lead to the creation of

environment which might influence individual behaviour and which are therefore more easily changed.

The second benefit of a behavioural approach is that it emphasises the rationality of individual behaviour. Even where the most unpredictable or strange behaviour occurs, the first questions to be asked are 'what function does this behaviour serve - what happens to this person when it is displayed?' and 'when does this behaviour happen - under what circumstances is it displayed?' These questions provide a tool to unravel sane behaviour in insane circumstances. The approach treats the individual as sensible - as the person who understands most immediately how to maximise the benefit to themselves under the prevailing circumstances. This also lessens the chance of 'blaming the victim' - of saying that unwanted behaviour is there because the person is bad, or mad or sick, instead of looking for the ways in which the environment produces and supports that way of behaving. In this sense behaviourism has the same kind of radical potential as the sociology of deviance for taking the part of the individual against the situation in which they find themselves.

The third benefit of the behavioural approach is that it has proved more effective in tackling a wider range of issues in understanding human behaviour than other approaches. This is particularly true in the field of serving people with long-term disabilities, where its focus on environmental change has played a part in the improvement of services. The power of the behavioural approach has, of course, been a double-edged sword; bastardised perversions of the approach have been widely abused as an instrument of social control inside poor-quality services. But used within the broader context of ideas about the mission of services like the principle of normalisation, the behavioural approach tends towards effective action on behalf of the people served.



**Achieving Change in Services**

Despite public scandals about neglect and ill-treatment, residential services for people with mental handicaps have been remarkably resistant to change. In the hospitals in particular, although there has been much expenditure on improving the physical environment and staffing ratios (from a very low baseline), the social and psychological life lived by people in hospital has probably not changed very much in the last 18 to 20 years. The predominant activities in most services (day or residential health service, social services, private or voluntary) are sitting around with nothing to do, or tinkering with trivial tasks as 'occupation'; there is only marginal investment in extending people's experience and skills. Rarely is this integrated with the daily living arrangements, so that one hand undoes the work of the other. Levels of interaction between staff and the people they serve are often extremely low (for many people being spoken to only every hour or two). This deprivation is especially marked for those people with severe and profound mental handicaps, who are most in need of help to organise and control their surroundings.

Paradoxically, while the front line of services has changed so little, the organisations which deliver them have suffered constant reorganisation, so that long-term policy planning has become more and more difficult. Despite significant reorganisations in 1968 (Salmon Report), 1970 (Social Services Act), 1972 (Local Government Act), 1974 (National Health Service Reorganisation Act), 1976 (Resource Allocation Working Party), 1982 and 1985 (National Health Service Reorganisation and Griffiths Report) two problems faced by staff running services for mentally handicapped people remain much the same: the unhelpful division of responsibility between agencies and the shortage of resources.

The division of responsibility between health and social services for providing residential, day and general support services for people with mental handicaps in

Britain has often been the target of critics who propose a unified national service. It is, however, just one example of the difficulty of collaborating across administrative boundaries. Even if it were politically possible or desirable to create a unified mental handicap service, this would still leave the problems of working with housing and education agencies and might itself increase the segregation of people with mental handicaps and the reluctance of mainstream services to address their needs. The alternative, being pursued slowly, is to develop better mechanisms for joint work, initially through the creation of mechanisms for joint planning and joint funding, and increasingly through arrangements for the joint operational management of services at local level.

Resource constraints pose a dilemma in terms of whether to pursue the goals of *coverage* or *excellence*; whether, if good services for all might cost more than the government seems prepared to spend, to settle for mediocre services for everyone, or whether to have some excellent services while others remain unimproved. Official guidance tends to favour uniform mediocrity, arguing that 'the best can be the enemy of the good'. Although this may mean that everyone is lifted above the most appalling levels of deprivation, it has serious potential drawbacks. If the motivation to change, and the commitment of resources, is spurred on by the deprivation in existing services then lifting them all above some sort of threshold will kill that drive to do better, as people turn to other issues. Similarly, if all services achieve about the same for the people they serve, then the lack of exemplars which represent the 'leading edge' of service provision will reduce the drive for others to catch up. If, as seems likely, service organisation and the outcomes achieved do not progress one step at a time, but can be characterised as occasional leaps forward interspersed with long years of relative inactivity, then having some services trying to make that leap forward is likely to be more useful than everyone fumbling and hesitating on the brink. In answer to the question 'what is the purpose of developing really good services when economic recession means not everyone can have them?' the answer is first, to keep the flame alive, so that when resources become available there are models of excellence to be adopted and second, to show that the deprivation and failure of existing services is their own product, and not to be blamed on the people they serve.



## *The Project Team*

It is within this context that the group of people planning to set up a new service providing staffed housing for people with mental handicaps will come together: high aspirations generated by the philosophy of normalisation and the evidence of what can be attained in ideal circumstances, complex organisational circumstances in which to make the new service happen, and continual attrition of resources and resource expectations.

The project team needs to include people in the right place in the host organisations and people at the right level. It is probably essential that members include people from both social services and health, since effective collaboration by these two agencies is crucial to providing good services to people with severe and profound mental handicaps. Someone with a housing management background, either in a local authority or in a housing association, will provide more relevant experience in property acquisition than staff of either health or social services are likely to possess. In terms of the seniority of staff, the team needs to include people senior enough to be able to make decisions without needing to refer back for approval all the time, yet junior enough to be able to spend the time it will take to do the work of project definition, finding housing, identifying potential service users and so on. Typically, teams set up to develop new services either include people so junior that whatever their good ideas they have no authority to see them through, or people so busy and important they never do the day-to-day work. In the first case the service never happens because enthusiasm and commitment is frittered

away while committees consider proposals, and in the second the service never happens because no-one ever goes and finds the people, the houses and the skills to make it happen.

Typically, the people who make up the project team will have other commitments, so that developing staffed housing for mentally handicapped people can occupy only a proportion of their time. Throughout the process of setting up new services then, each project organiser will face competing demands on their time which they will have to manage. This book does not offer guidance on how to do this, but it is important that the host service agencies recognise that the outcome of the service development process, in terms of the details of how the services were set up, how they work and what they achieve or fail to achieve for the people who use them, is the product either of the deliberate action of the project team or of omissions because they were too busy to attend to everything. The agency cannot rely on good fortune to hope that the services turn out well - not least because, since these services run counter to many of the pressures and tendencies in traditional models of care, failure to tackle an issue is likely to result in it being decided in the traditional way.

As a small group of people come together to take on the development of staffed housing, one of the first tasks they must address is building a coalition of support for the project, which they can use as a network both to give early warning of potential difficulties and to provide support when the project proposals are criticised or undermined. Identifying members or potential members of this coalition, making contact with them, keeping them informed, mobilising their support when needed and showing appreciation of their interest are activities just as important as finding houses or appointing staff.

What this network looks like - which places people are drawn from, where in the different organisations people are located and so on - will vary with the project. Within each network, however, there are likely to be people playing one of a small number of particularly important



roles. The most obvious group are those who might be called *decision-makers:* people who can directly alter the course of the project and with whom the organisers will need to spend time preparing the ground carefully in advance. Examples of such decision-makers are planning officers in the local authority, fire safety advisers in the host organisation, architects or supplies officers and so on. The second group are *sponsors* (what in the management literature are sometimes called 'project champions'). These are people in each of the organisations involved who are senior enough to be able to intervene to overcome administrative obstacles, though they are too senior and too busy to concern themselves with the day-to-day progress of the project or necessarily to develop a sophisticated understanding of the principles or philosophy on which it is based. These are the people who can be called on to circumvent or over-rule silly impediments generated by decision-makers. The third category of people to include in the network are *supporters*: these are people of some standing who can be relied upon to express more or less unconditional support for the project when called upon, even though they too may not have much grasp of the details.

It is possible to conceptualise membership of the coalition as including other people too - like opinion-leaders who take an interest but are unpredictable in their views when they express them and so need to be kept especially carefully informed and briefed - but these three kinds of people are the basic set. As the project progresses, membership will change and the stresses of the moment will occur in different areas or around different issues. The point is that, although these tensions are likely to arise whatever the project organisers do, the existence of a well-developed and maintained coalition of support will enable the stress to be shared and will increase the resilience of the whole project.

## Defining the Aim of the Project

Wolfensberger suggests that the overall aim of services for devalued people is the creation of valued social roles for each individual, and that this requires both a focus on the competence of each person and on the image the service presents about them. O'Brien has operationalised this objective as 'five essential accomplishments' of services for people with mental handicaps. These are:

Presence: the extent to which the service ensures that the person served is present in the mainstream of social arrangements for living, working and leisure.

Choice: the autonomy of the individual both in making decisions about everyday issues and in determining the major directions of their life.

Competence: the personal growth of the individual in competence and experience, including the level and variety of activities in which the service helps the person participate.

Participation: the range and variety of friendships and other relationships the person possesses.

Respect: the experience of being valued by other people as an individual member of their community, and the perception of the individual by other people.

Of course there are other goals (such as health, or personal safety) which need to be attended to in order to facilitate the achievement of good outcomes in each of these five areas, but these represent the core accomplishments of a good service and they are an important yardstick against which to judge any plan or service in operation.



*Choice and Control*

Although these goals recur again and again in the rest of this book, it is worth paying special attention at this point to the choice and control exercised by the individual receiving services. The project organisers have to work out how to reconcile the desire to build services which respect each individual's right to choose, with the desire of the service to impose some control on the people it serves in order to achieve its stated objectives.

Making good choices is a skill which can be learned. It requires that people have the breadth of experience to be able to distinguish different options; since many people in mental handicap services have been denied this breadth of experience, it will often need to be an explicit goal in individual programme planning. To make use of their experience, people also need to know that what they say matters - that if they decide to do one thing rather than another, people will respect that decision in so far as they are able. This means constructing services that respond to the people who use them rather than only to managers and hierarchies. Finally, people need to be able to express their preferences, and for people with disabilities of language or communication this may require much ingenuity on the part of the service staff.

Failing to address these issues is not any less controlling: it simply means that the choices open to people will be more restricted the greater their disability. For many people with severe and profound mental handicaps, services offer only one effective choice - do nothing or sleep. When people need the assistance of others to engage in almost every activity, and when they have difficulty making their needs known, choice depends on making that help available. Thus, an apparently permissive or liberal philosophy of *laissez-faire* can be as restrictive as the regimentation of the archetypical total institution.

Following through with the choices people make does not mean forcing difficult choices upon them without support. Having failed to help people develop the capacity

to make informed judgments about courses of action, it is not helpful for the service then to throw all responsibility on to the people it is supposed to serve. If choosing is a skill it can be taught; teaching it implies gradual exposure to increasing levels of difficulty with lots of safe practice and lots of help. This means that the service agency will have to live day by 'day with the tension between knowing what is best and backing people's choices: when it knows best it can validate this judgment by using outside referees (like citizen advocates) and it can review the extent to which the individual is being helped to be more able to make the choice next time.

It is of course often very difficult to know whether someone with major disabilities of communication and learning is indicating a preference, especially an informed preference. One strategy is to work through a hierarchy of approaches until finding the one which appears to give the best opportunity for the person concerned to choose on the basis of their own experience and judgment. People can be asked what they want; they can be shown pictures or models to augment the explanation; they can be asked several times to check out the consistency of their preference; they can be given samples of the different choices available and then asked which they prefer; or they can be given both choices for as long as it takes until either they indicate a preference or staff notice a clear preference from their behaviour. In the last resort, representatives such as advocates can be used to make a proxy decision.

The behavioural approach suggests that, even where people are so heavily handicapped that they do not appear to indicate any preference in most situations, they can be taught to respond. Who knows if the woman labelled as profoundly and multiply handicapped sometimes raises her arm to attract attention when a member of staff walks by? But if *most* times she raises her arm the member of staff notices, stops what they are doing and spends some time with her, and if this is a rewarding experience, she will learn to summon staff.



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## 2. Project definition

In the project definition phase, the people involved in setting up the new service must work out its main features - who will be served, what are the assumptions and principles on which the service will be based, how it will relate to the host organisation, and so on. Project definition is important because most decisions made at this early planning stage exert a continuing influence on the operation of the service and some can be difficult to change later. This applies most obviously to building design and iocation, issues which have tended to dominate the planning of residential services; but it also applies to decisions about staff qualifications and admissions policy, for example. Once staff are appointed or clients are in residence it would be hard to move them, even if this were desirable. Failure to spell out basic principles can also lead to decisions being taken by default, such as when too many families are promised places in a new service by professionals working in the absence of a clear policy.

Careful thought about the details of a proposed service is important for another reason. When actually setting up a service many decisions and compromises will have to be made in translating principles into practice. Once these particular decisions have been made, there will be a tendency among everyone interested in the project to identify them as 'ideal' solutions and to assume that they need not be questioned. For example, the first house will have a certain number of places. Although this may have been a compromise with a larger size than was wanted in order to get the scheme off the ground in the first place, others may latch onto the size as a central element in the service and expect to hold to it in subsequent developments. This means that, in working out the proposal, it is important to indicate where a range of options will be available (and particularly where the first development may be more conservative than later

schemes); it also means avoiding arguing that a particular compromise is ideal just to get it agreed. The project needs to maintain the flexibility to develop better responses to individual need, both in the proposal document and in negotiations.

This chapter sets out some of the fundamental issues and questions that hhve to be determined as a new service is set up. New services are probably more likely to meet the needs of their users if each issue has been consciously addressed in the project definition phase. It will also be clear in the move from project definition towards practical implementation what compromises and trade-offs shape the service. It is important that these short-comings are recognised not only so as to maintain the commitment to correct failings in the future but also so as not to create an improved but still essentially second-best service as a new orthodoxy.

The first part of the chapter discusses key issues in service development and covers the type of housing service to be provided and its relationship with other services for people with mental handicaps. This is followed by a section devoted to gathering information about potential users of the service at the beginning of the provision process. This deals with gaining enough information to choose an area in which to start service development, and to define the broad scope of the project. As development proceeds, increasingly more detailed information about specific groups of people will be needed so that the needs and preferences of individuals shape the kind of service provided.

## Key Issues in Service Development

Before working out the details of the first group of staffed houses to be provided, there are a number of general issues to be clarified about how the service will develop. These may be considered in four groups: the kind of housing to be provided, the people to be served,



which agency will be responsible for the service and the relationship between housing and other services.

### *Range of Housing*

The first group of issues concerns the need for a range of housing. There are two aspects to this: first, different people will prefer or need housing of different types, and second it will be much harder to obtain property if restricted to only one type. It may seem obvious to say that there should be a conscious plan to use flats and maisonettes as well as terraced, semi-detached and detached houses of different sizes, but if this is not clearly understood from the outset, temporary obstacles (such as fear about revenue costs) can become permanent assumptions about what it is intended to do.

Similarly, there is a range of options in acquiring property for staffed housing. Different routes (buying, renting, using housing associations etc.) are dealt with in the next chapter, but the important point here is that these routes are not mutually exclusive. It will be sufficiently difficult to get attractive housing where it is wanted without being confined to one mode of acquisition. One particular approach may be preferred at first because it is quicker in the short term, even though it has other disadvantages (like buying a house through the health service because it has ready money, even though it will be harder to furnish appropriately) but it is also important to cultivate other sources and that the host agency expects such an entrepreneurial approach.

Concern about the 'optimum' size for group living will surface when discussing the range of housing. Usually this has more to do with fears about revenue costs of staffing than about concern to find the best arrangement for each person served. The goal may be to offer everyone the opportunity to live on their own or with close friends or partners; this is after all the commonest choice made by other people. Since there is probably a minimum viable group size for staff (see the discussion in the next

chapter), reducing the number of people served in each location will increase costs unless the staffing mode1 shifts towards family placement or life-sharing. The problem with these approaches is that they effectively make people work for longer hours with less clear conditions of service for the same money. As a service model, family placement or life-sharing may therefore offer benefits to the handicapped people served that are in direct tension with the quality of life of the people caring for them.

*The People to be served*

As well as sorting out the range of housing options, the range of disabilities among the people to be served needs to be considered. In a better service, people would get the help they need without so much attention to classifying them; but present circumstances involve trying to develop a new service for small numbers of people in a relatively disorganised and impoverished climate. If not planned carefully, the project will be faced with referrals of many more people than it can possibly cope with. It is important to clarify that the people served have mental retardation as their primary disability and, since it is staffed housing, that these houses are intended for people with severe handicaps who need a lot of help most of the time.

It is also necessary to consider how people come into and move out of the staffed housing service. Is the service providing a progressive sequence of different residential settings through which people move as they become more competent, or a secure home for life? These are not simply alternatives: it may be attractive to reject the progressive sequence because it makes people move house, but planning a home for life may not encourage individualisation and independence. Leaving home or moving house provides opportunities to live with new people (with whom one chooses to live) and to tailor the home more closely to individual preferences and needs. It helps to separate out the two issues muddled up by this



dichotomy between enforced moving and never moving. First, the level of support can be varied in a service independently of the setting. Although often difficult to organise because of administrative policies, there is no reason in principle why people should not have more or less staff available as they need them in the same house. Second, the service can guarantee security without this having to mean that the person stays in the same place all their life. It would be possible to guarantee a minimum standard (such as a commitment to enable the person to live in the staffed house) but to accept that the service would support a person in a more independent setting if this best met their needs.

**A** related issue is where the service stands on attempts to return to institutions people who have problems which are hard to work with. Sending people back, apart from any damage it may do to the individual, may strengthen prejudice that handicapped people should not live in the community. On the other hand, failing to manage a person's problems can make a mess of their life and those of other people who live and work with them. No one has all the answers to help people with major problem behaviours (hospitals cope only by making fewer demands and by tolerating more of the problem out of the public gaze). A commitment to keep trying is, however, a prerequisite for learning how to help the individual and developing the expertise to do so consistently and confidently. In terms of developing the service one decision is to discriminate against people with problems until the staff of the new service have enough experience to cope. Clearly, this approach runs the risk that the service is never ready, or that staff and managers gradually redefine its scope as only for people without these problems. Alternatively, the project team can recognise that they will only learn through experience and therefore opt to include some people with more challenging problems at an early stage, allocating the resources and effort needed to meet their needs properly. What has to be certain is that the service maintains the commitment and momentum to provide for those who are

hardest to help; that it does not 'forget' people. One part of this should be a policy commitment so that everyone understands from the beginning that the service is about meeting people's needs rather than sending them back when they need most help. No doubt this approach will be strongly challenged by some people with influence over the project who will be suspicious of simplistic arguments for community care. So, when staff need a swift intervention, help has to be available and this means extra staff and skilled guidance and support; but it also may mean money to pay for damage during a difficult time or to rent a flat for one person and some staff for a few weeks to try to sort out a new strategy for coping with the problem.

Similarly, thought needs to be given to how people get into the service and in particular whether the service is designed primarily for people now living in institutions or for people living with their families. Clearly these are not mutually exclusive, but priorities need to be thought through so that prospective consumers and their families have realistic expectations. One approach used in Andover and Cardiff has been to designate catchment areas for individual houses or for groups of two or three houses. The catchment areas are drawn to include the number of handicapped people who can be served by the houses, giving first priority to people already in residential care or on waiting lists and then keeping remaining places for people currently living with their families.

The catchment area approach has a number of strengths. It gives people in the catchment area an assurance that they will be served; it maintains the local base of services by preventing people being housed away from their own community; it achieves a balance between serving people in institutions and those from their family homes, giving priority to those in residential care or those who need it urgently; and it is easy to spell out the rules that are used to draw the catchment areas (compared for example with the workings of 'admission panels'). The disadvantages include that people who need a service soon and are just outside the catchment area find it hard to see



why they should wait (especially if services are being developed slowly); that people are arbitrarily grouped together by locality (although of course actual implementation should take account of friendships and preferences); and that its apparent objectivity conceals the need for a consensus about admissions policies which, if absent, will in any case weaken implementation.

The commonest alternative to a catchment area approach is to design the scheme to serve either people from institutions or people from home. It is not clear whether it would be possible or desirable to do this on a service-wide scale and the tension between the needs of these two groups would need careful management to ensure that the housing service did not use all its resources on one group of consumers. This approach also has another possible disadvantage; because someone has to select people to be served from what is usually quite a large potential consumer group, the admission process can become dominated by bargaining about the merits and demerits of handicapped individuals. The catchment area approach, by using a more or less arbitrary set of rules to narrow down the group to be served, then lends itself to the interpretation that each handicapped person has a right to that particular service there and then.

As well as answering these questions about who will be served, the organisers of the project also need to think about how the service will cope with population growth and fluctuating demand for housing. New consumers will not arrive in groups to be housed together; as new people need housing, their needs will have to be met individually, without incurring the wrath of those who look at revenue costs. There are several obvious approaches:

1. Placing people individually as they need housing. In this model, people only live in groups in the first generation of developments; after that, they are housed individually (unless they want to live together). This would be an ideal solution but most services at present will not have the money to fund

the staffing needed to adopt this model, except in particular individual circumstances.

2. A variation of the first approach would be to house one person until the next came along and then move to a two-person flat while waiting for the third, etc.

3. Instead of moving people to bigger accommodation, the first person could be housed in a house on their own, and extra people would come to live in this house until it was full. Staffing levels could be varied (perhaps starting with live-in staff) to match the number of people living together.

4. If the third approach were used, the available places in the house could be used for short-term care until long-term residents were found. If this option were used, it would be best to restrict short-term care to people whose eventual home would be in the same house or flat, to minimise disruption to the people already living there. This kind of short-term care might also only be needed in the absence of enough good-quality long-term care and family support services.

In practice, several of these approaches will probably be used depending on individual circumstances and current pressure about costs. Therefore apart from discussing what might be done, it will also be necessary to review the arguments about costs of different types of service. These relate primarily to staff costs and are dealt with at length in Chapter 5.

*Agency Responsibility*

The third group of issues concern which agency should be responsible for the service. Staffed housing is being set up by social services departments (sometimes with health service funds) and by health authorities, and in some areas there are proposals for health authorities to set services up but to transfer them to the local authority within a decade, or for both sets of authorities to create



joint structures to manage the new services. The argument in favour of social services management is that it is consistent with the move from a 'medical/nursing' model to a 'social' model of care; that it will be easier to develop really local, homely services away from the framework of hospital planning and management; and that it will be easier to access generic resources including social security funds from within local authority social services. One major difficulty has been that all the available resources have been locked up in the health service, but recent developments in legislation and government guidance have removed this obstacle.

A bigger problem is that up until now mental handicap has been a peripheral issue in most local authorities and so social services departments have lacked expertise in the area. This is a particular problem in relation to the care of the most severely handicapped adults, especially those with major behaviour problems or added physical handicaps, where referral to the health service remains a common response. This lack of practical expertise is mirrored in many places by policies and plans which are as outmoded as anything in the health service, and equally poor provision results. It must remain doubtful whether, if the service was simply transferred to local authorities, significantly better developments would result, at least in the short term.

Of course the issue is not one of making a simple choice and never departing from it. The problems of local authority services are largely due to lack of resources and inexperience; the former is beginning to be overcome by new opportunities for resource transfer and the latter is changing as day care services increasingly provide for the most handicapped people and as community-based residential services are set up. In the longer term, it does make sense for local authorities (housing as well as social services departments) to play the primary role; what is required in the interim is a partnership between services that draws on all the resources and expertise available.

In terms of a strategy for development, this might mean that starting some things in the health service but

planning to hand them over later, or it may mean opting for a jointly managed 'patch' service, or for transfer of funds to enable local authorities to run the whole service. The alternative of trying to define each agency's responsibility so precisely that they can each develop their services without much reference to the other does not work. As soon as there are definitions dividing responsibility there are 'grey areas' and attempts to pass responsibility for people between services. Failure to develop partnership at the policy and planning level of the agencies also mitigates against effective collaboration in operational management and service delivery. Thus, although division of responsibility may allow one agency to get ahead unencumbered by lack of commitment in the other (as it did, for example, in Wessex in the nineteen-seventies) it may not help develop effective partnership in providing local services.

Whichever route to partnership is followed, four sorts of mechanisms for cooperating will be needed. There will need to be arrangements for joint decision-making about service development and the day-to-day running of services at the level of the locality being served. There will need to be mechanisms for the transfer of resources as people formerly served by the health service are taken on by local authorities. Careful procedures will need to be worked out for tracking the progress of individual handicapped people so that no-one gets lost in the system, or comes back to the hospital gates. These will also need to take account of people living in the community who may need housing, so that they do not have to seek hospital admission in order to be 're-settled' locally. Finally, the agencies will need to use their personnel policies imaginatively to help foster a common staff identity and sense of teamwork, not least by trying to ensure that people with different employment backgrounds who do the same job receive the same terms and conditions of service.



*The Relationship between Housing and Other Services*

The last group of general service design issues concern the relationship between the staffed housing provided by the host agency, and other services for people with mental handicaps.

The first question here is to what extent should housing be separate from local services to mentally handicapped people living with their families? On the one hand, it is important that people's houses are regarded as their own private dwellings and that family services do not intrude on residential settings (for example, by trying to make people's houses into clinics and offices and advice centres as well as homes). On the other, if some short-stay opportunities are provided for future residents, families may look to the staff there for advice and help and the staff may well be in a good position to provide it.

Two types of service response to this issue seem to have been developed. The most common is the separate family support service provided by staff in a 'community mental handicap team' or its' equivalent. Typically these workers are qualified nurses and social workers, working from administrative centres and carrying large caseloads. Their work together is coordinated through a locality-based case management system like individual programme planning. The advantage of this model is clarity of purpose: the residential and family support staff have clearly defined and separate roles. The disadvantage is that, because of their caseload and their seniority, family support staff may see their job mainly as providing an advice service or case management service rather than substitute care for the handicapped person (which may be what the person needs).

The other common approach is that staff in a residential setting are expected to provide an 'outreach' service to local families. Although this provides the potential to second staff to help care for the handicapped person as well as to provide advice, it runs the risk that either the residential or the family support function suffers in competition with the other. It is also

complicated by the common assumption that better domiciliary services prevent admission to residential care and so can be used to ration access to residential care. While this may be true where residential services are of appallingly poor quality (so that families will endure much more hardship to support their handicapped member at home) it need not be true when services of good quality are available. Then, many more people with mental handicaps and their families may decide that leaving home, in the same way as other people leave home in early adulthood, is the appropriate choice.

A third alternative which could be borrowed from social work practice is a 'patch' model of service. The NIMROD service (a comprehensive community-based mental handicap service in Cardiff) comes close to using this approach. In the 'patch' model, a team of staff is given the task of providing all the primary services to clients in a particular local area. The 'patch' is small enough to have the benefits of coordinating small numbers of people. Taking it to its logical conclusion, the patch team would have enough budgetary and managerial autonomy to deploy staff in family homes or in residential settings as individual handicapped people needed them, without involving so many staff that either service had too many new faces. An obvious extension to this is to have the team deal with the home-finding function as well, renting or buying property and disposing of it as individual needs dictate. It might even be possible, especially as alternatives to traditional day care become available, to include day services in this approach. This kind of jointly managed local service would represent a logical extension to joint planning and joint funding.

## Defining the Client **Group**

This section deals with the task of narrowing down the focus to identify the first group of people to be served. Since staffed housing is a personally-tailored service the



people developing the project will have to meet the people who are going to be served, so that the provision of housing and support to meet their needs can be worked out.

Since residential services using ordinary housing for severely people with mental handicaps are still relatively new, a project will often be proposed in an area with few, if any, services. Under these conditions it may be useful to develop a strategic plan for a whole county or district. This has the advantage of allowing resources to be earmarked against a timetable and it clarifies catchment areas for locally-based services so that sensible boundaries for future schemes are not pre-empted by early developments.

However, it is not always necessary or even desirable to start with a strategic plan. As a first move, a strategic plan can be the focus for an extended debate about the type of services to be provided - about whether, for instance, to build new institutions. Unless confident of winning this debate, proponents of ordinary housing might better direct their efforts to establishing pilot schemes before attempting to generate a policy for a whole territory. It is also important to note that all strategic plans need continuing review, not just because funding priorities change but also because more comes to be known about the individual handicapped people involved and service personnel become more skilled at developing alternative housing options. In such a rapidly developing field, a strategic plan is simply a vehicle for gaining commitment at the beginning of the service provision process, rather than a detailed blueprint to be followed to the letter.

Similarly, a common assumption at the start of a project is that what is needed is a survey to establish a mental handicap register. However, this is not necessarily the best way to proceed. To develop a good register takes time and effort and resources and it will therefore probably delay the introduction of new services. It may also be wasteful of resources: spending money on survey staff to find that there are many more people than it can

be hoped to serve in the short term, instead of concentrating resources on determining the needs of individuals at the time when there are the resources to meet them.

In fact, detailed information is not required on all people in the territory at the same time, nor is it all required at the beginning. A practical alternative involves a four stage process in which an outline strategy can be developed on the basis of some readily available data and more detailed information is only required as the resources become available to meet the needs identified. The four stages are:

1. The whole territory is first subdivided into areas for which services can be separately planned by considering basic demographic information.

2. Planning norms or epidemiological prevalence rates are used to illustrate the strategy, what the resulting average distribution of services will look like and the flow of development and its financial implications.

3. The numbers and broad characteristics of the people with mental handicaps actually in each sub-area of the territory are only established as planning proceeds each in its turn.

4. Individual assessments and the establishment of personal needs and priorities are only undertaken when the new service is ready to meet them - i.e. only a relatively short time in advance of beginning to look for suitable housing, day-time and leisure opportunities.

Differing emphases can be given to each of these four steps depending on the local climate for innovation: it would be possible to spend as much effort on dividing up the territory and showing how all the services will eventually fit together as on choosing the first target area and meeting the people there - but in a less enthusiastic climate it might be just as well to devote more attention



to one area and give only an outline account of how the strategy could unfold.

### *Dividing up the Service Territory*

To divide the territory into areas which can be used for planning, requires maps, data on current and projected population and its distribution and some knowledge of other features of the territory such as roadways, rivers, cultural divisions or historical affiliations which may divide the total population naturally into separate communities or may provide a means by which other communities are given a sense of identity.

Using this information, the territory can be divided into mutually exclusive sub-areas, each of which is internally cohesive and centred on a population cluster. It is important to avoid creating tracts of rural land which are not linked with a centre of population which has adequate community resources. Instead, these areas are identified with the town with which they have their closest links. In a similar way, subdivision of large urban areas is achieved by considering the location of neighbourhood shopping and amenity centres and natural internal boundaries such as major roads and parks. These areas do not, of course, need to be of similar geographical or population size, although areas of much more than about 60,000 people are unlikely to meet these criteria.

### *Illustrating a Strategy*

Given the basic division into planning areas and the general decisions already referred to about the form of services to be provided, an illustration can be prepared showing how the programme of development might unfold using the agency's resource assumptions. The number of people needing services in each area can be estimated using available epidemiological data, either from one source (such as the studies in Wessex,

Camberwell or Sheffield) or averaged in the form of the planning norms in the 1971 White Paper *Better Services for the Mentally Handicapped.* If norms derived from a small-scale study are used it will be important to make sure they are applied to areas which have similar demographic characteristics, since prevalence varies between inner-city and rural areas, for example. Even more important the plan should make quite clear that the projections are illustrative, since the prevalence of people in long-term care varies dramatically between small areas and over time.

At the end of this stage of planning, the project organisers should be able to satisfy themselves and the agency that the strategy outlined will result in a coherently constituted service, while also having preserved the freedom to adjust plans better to meet the needs of the people who will be served as the plan actually unfolds.

In terms of turning this illustration into real service development, there are also issues to consider about deciding on the target area. It may be necessary (for example, for political reasons) to develop services a little at a time in each area of the territory. To do this involves either keeping up-to-date information and maintaining liaison for everyone involved (all the potential users of the service but also all their neighbours, local planners, estate agents, housing associations etc.) or devolving project management to a local team in each area.

Often it will make sense to start in one of the areas and develop a relatively full range of services there before beginning elsewhere. This patch-based method of progressing makes it simpler to deal with all the different people involved, by restricting the geographical area of interest and therefore the number of potential service users and other collaborators. It can also help by focusing effort on building support at the very local level where it is needed.

In deciding in which area to start development, there are four criteria worth considering:



1. The numbers of people with mental handicaps and their apparent needs. It may be appropriate to start where staff in the providing or other agencies report the most pressing problems. It needs to be borne in mind, however, that there may be major needs not yet detected in an area of apparently lower demand because people are not getting any service and have given up asking for help.

2. The 'readiness' of an area in terms of service provision and sources of support. For example, it may not be so appropriate to develop the first schemes in an area with no day care opportunities or with a large hospital nearby; on the other hand, planners may want to provide in an area because it has very few services. Similarly, the presence or absence of local supporters in the organisations it will be necessary to work with should be taken into account.

3. How quickly work can start in a given area: How available are money, housing, a potential workforce and the political willpower to see the development through?

4. The extent to which the boundaries of the area are perceived as natural: If they are more or less arbitrary then people just outside the area being served will complain until a service is developed for them. This pressure can lead to the agency making rushed decisions that turn out to be second-best and that distort the pattern of service development. This is less likely to be a problem if it is possible to concentrate in an area that can be defended as a logical starting place.

Deciding on one target area does mean further restricting eligibility for the service, by geography, family ties or place of residence. However, given a commitment to provide a comprehensive service the decision to concentrate development on each area in turn is really the same as imposing any staggered timetable on the

unfolding of the plan. Unless everyone receives a service at once some will have to wait. The number waiting does not depend on whether development proceeds area by area or a little at a time everywhere.

*Identifying Possible Service Users*

The next step is to identify all the people who might be eligible for the services to be developed. Up to this point, planning has been carried out on the basis of rough estimates derived from prevalence norms for the group of people with mental handicaps it is intended to serve. Now it is necessary to find the real population from which the users of the service will be drawn.

If it has not already been taken, a decision now has to be made about the people to be served and how hard the new service will try to locate people who may be eligible. Potential users of a staffed housing service could be living at home and attending some kind of day service; they could be living at home but not attending services; they could be living in a residential service within the territory served by the staffed housing agency or they could be living in residential care somewhere away from the area. It is particularly important to be clear about whether the service is intended for people now living away from the area. Although it may be much more convenient to forget people living away in institutions or private residential homes, it may not be right. Where people's claim to local services is based on actual or potential family or friendship ties ignoring them at the outset may simply postpone the day when their local contact sees the new service and tries to obtain it. Even where there is a weak case for moving back to the locality (where there are no real contacts or the family have severed their ties) it has to be asked whether someone can legitimately be left in impoverished surroundings when they could, if they were able to speak for themselves, insist on taking up their place in a better service. It is of course essential to sort



out which people will be offered a service before contacting any of them.

Different strategies may need to be used to find everyone. Where there are local services, it is relatively easy to identify those people currently using them or in touch with them. Since services have usually been scarce, many have ignored geographical boundaries in trying to serve people with the greatest need. Care needs to be taken therefore to distinguish those people who come from the target area. It is also important to find out whether there are people who are not using the available services, either never having used them or having ceased to use them (people who drop-out rather than face attending adult training centres, for example). Tracking people down from old service records or registers often poses a dilemma: if people are not contacted they may be in real need of help and they may present to the service in crisis without warning; on the other hand, they may be living independently and resent any attempt to involve them with a service which has had such a strongly stigmatising history.

People with local ties but who have entered residential care elsewhere often pose problems of identification. Such people may be scattered far away and their relatives or friends may not be in touch with local service agencies or with voluntary bodies. Where a mental handicap register exists which is reasonably up-to-date and which surveys services outside the local territory (both quite rare circumstances) it can be used. Otherwise it will be necessary to write to many residential facilities asking whether they have people from the territory, if some people are not to be abandoned from the outset. Surveying the hospitals in contiguous health regions and the special hospitals will track down most people, although individuals will continue to become known to the service from hospitals much further afield. This is unavoidable and is, in any case, something with which the service has to cope as families with members who are mentally handicapped move into the locality served.

This process of identification will yield a list of people who belong to the territory of interest and may need the service being established. This list has to be refined by establishing individual needs at two levels; initially by finding out who needs staffed housing (that is, who needs housing and also fulfils the criterion of level of help needed from staff) and later by moving on to establishing the individual needs of the small number of people who will be served by the first few schemes. At the first level, assessment involves obtaining the information needed to decide eligibility for the service - usually including each person's age, address, kinship ties, and some overall indication of the level of help they need - and determining whether the person requires a residential service.

The overall estimation of need is often attempted using short assessment forms completed by staff in a residential or day service used by the person served. Common examples of these forms are the Adaptive Behaviour Scale and the Wessex Social and Physical Incapacity/Speech, Self-help and Literacy (SPI/SSL) Scale, which has been widely used in its original form and as amended by the Development Team for the Mentally Handicapped. This type of approach is cheap and easy because all it involves is sending out forms; much of the information so obtained, however, is so inaccurate as to be quite useless. Both the Adaptive Behaviour Scale and the Wessex SPI/SSL Scale suffer from problems of reliability, in that two staff filling in the forms separately will produce quite different profiles of the same individual, especially in the area of problem behaviour. There are also problems of validity, in that some of the items are of questionable value. For these two scales the issues of reliability and validity have at least been addressed in the research literature; the growth of registers of people with mental handicaps has encouraged people to invent and use new types of scale without any attempt to check them out first.

It does not take much insight to see some of the problems of trying to use this method of finding out



about people. First, the staff who fill in the forms may not understand exactly what is intended by all the questions, they may be busy and too harassed to complete them carefully or they may spend so much time filling-in useless forms they may have given up taking any interest. Second, in poorly resourced services staff levels may be so low that staff actually do not know the people they care for well enough to answer the questions (so that people do not know how often someone needs help to use the toilet if the common practice is to let people sit in soiled clothes); shift patterns and staff rotation between groups of people served in hospitals also disrupt getting to know people (day staff filling in the form not really knowing whether someone is continent at night, for example). Third, the deprivation of the services themselves directly influences the behaviour of the people who live there, so that any assessment is as much a measure of the environment as of individual capability (so that deficits of behaviour may simply reflect the lack of opportunity, and excesses like outbursts of temper may be a reasonable response to unreasonable circumstances).

The implications of this are that, even where such information already exists and is up-to-date, all those people assessed as having anywhere near the level of need the service intends to address must be visited, so that the project organisers between them have first-hand experience of the people to be served and the situation in which they currently find themselves. This process of gathering information about the people to be served (and imparting information to them and their families), once started, needs to continue throughout the development of the project, so that the project organisers neither raise hopes and fears which are then not resolved nor surprise people with difficult decisions without preparation.

The types of information needed include gaining an impression of the current environment and the major events and experiences of the individual's life to date, so that the individual programme formulated in the new service can accommodate to these experiences and the interpretation of individual behaviour can take into

account the environment and its history. Information is also needed to begin to map out the individual's strengths and needs (especially needs which may require special management such as disability or problem behaviour) so that an individual programme can be developed for the first day after they move and continue until the first Individual Programme Planning meeting is held (see Chapter 8). Individual preferences and the relationships and activities which people hold important and which a good service would positively safeguard is also needed. All this information can be written down in a standardised way for later reference, but the important thing is the personal knowledge of each individual so that questions about level of disability can be discussed rather than forced into an arbitrary assignment to fit a short assessment form.

In visiting people to find out this information, the project organisers need to check that staff or family members they talk to understand that the individual is guaranteed a place in the service, and does not have to pass a test of competence or acceptability to take it. Staff and families may have experience of services which only attempt to meet the needs of people with relatively high levels of competence and few problems, and this may make them (naturally) inclined to represent the individual in what they believe will be the most favourable light.

As well as finding out about the needs of possible service users in terms of their level of disability, it is also necessary to assess each person's need for housing. For people already in residential care, determining whether they require a residential service is not usually a difficult issue. For people living with their family, a series of discussions between the individual and/or their representative, their family and service staff will be needed to try to estimate the likely need for housing. Some people will be living with relatives who are under great stress or who are very elderly or infirm but where there has been no request for residential care. It would be unrealistic to expect all potential service users and their families to synchronise their demand for services with the



timetable for service development and some places will probably need to be set aside for named individuals. This requires an explicit recognition that the service will, during its first months or years, operate apparently under-utilised so as to maintain its readiness to meet the needs of individuals as their personal circumstances change. These changes might not only be events such as the loss of a relative; some families will have supported their handicapped member at home in the most adverse circumstances because of the appalling deprivation of available services, and they will want to wait and see whether the new model of care really is any better.

These decisions during the first level estimation of need for a staffed housing service will yield a list of actual people who will become users of the service in the territory of interest. As the service is developed, more detailed establishment of individual needs and preferences must be done by the service workers involved, and particularly by the staff who will work with each individual in the new housing.

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# 3. Finding housing

This chapter is about finding housing for people who are mentally handicapped, given the constraints imposed by services which have been geared to providing institutions of one sort or another. Property acquisition involves three kinds of issue; the sort of housing needed (where it is and what type of property it is), the different methods of obtaining property (whether to purchase or rent, which agency should undertake the acquisition) and handling public relations (including obtaining planning permission where this is needed).

For people without handicaps, these issues involve making compromises between preference and necessity. However, individual choice, although constrained, plays a major part. Services for people who are mentally handicapped introduce (even if inadvertently) all sorts of obstacles which make it harder to offer a person ordinary housing, let alone offer a degree of choice. Thus a considerable part of this chapter is really about how to overcome difficulties which have nothing to do with the individual person's need for help, but which reflect the insensitivity and inflexibility of service structures.

As with any individual, the general strategy for finding a new home must be to keep a range of options open so that, if one possibility falls through, others are immediately available. This is even more important when a service agency is involved since this increases the potential delay, the range of possible obstacles and the likelihood of missed opportunities; tackling each prospective property in sequence can seriously delay a housing programme.

It was suggested in Chapter 2 that a range of housing types and options should be acquired by different routes. This is both a more robust approach, providing more scope for individual choice and less risk of the whole programme encountering difficulties, and a better guard against the programme coming to be seen as the

mechanical replication of identical units irrespective of individual need or preference.

## Housing Criteria

### *Choosing Possible Neighbourhoods*

The first task is to identify the range of possible neighbourhoods in which to look for property. This only needs to be done thoroughly once at the outset of developing services in a particular place. Since the people planning services rarely live in the area where they are developing them, it must be emphasised that choosing possible neighbourhoods requires touring the area to see it at first hand rather than relying on maps or hearsay. Gaining some local knowledge by, for example, talking to the families of people to be served also makes sense and may be a good way of involving them in the process of bringing people back home (if their guidance is going to be followed, that is).

The first criterion for acceptable neighbourhoods is that they are residential areas rather than anything else. Housing people on waste land, in rural isolation or in industrial estates directly hinders their social integration, their access to community services and their image as ordinary people.

Desirable residential neighbourhoods will have a range of shops and amenities available locally (within walking distance) and will be near larger shopping centres. They will have good opportunities for access to these facilities (by public transport and by road) and they will be accessible to the families and friends of the people being served. Access to family and friends will be easier if the housing has been planned to serve people from the immediate locality. A good example of such a neighbourhood would be an established area of housing for people of different ages and family structures, with some corner shops or a local row of shops within easy



walking distance (with good footpaths and a relatively level journey crossing only a few minor roads), with two or three main public transport routes and main roads giving access to a large shopping centre about 10 minutes journey away. A much less attractive example would be an overspill estate on the edge of a town where only young couples with children tend to live, without local shops and poorly served by public transport.

Finally it is appropriate at this stage to plan so as to avoid creating neighbourhoods with abnormally high densities of residential provision for priority care groups. Here too, catchment area planning will help. But liaison with people planning for other care groups in the host agency and in other relevant agencies will be needed. Failure to attend to this issue means that several groups target the same neighbourhoods and, if the planners are not careful, they can inadvertently create ghettoes which risk 'planning blight'.

Having taken all these considerations into account, it will be possible to mark out areas on a local map where suitable properties might be found, and to identify areas where any property would be unsuitable.

### *Identifying Possible Properties*

What kinds of property are suitable clearly depends on the needs and preferences of the people who will live there. Once the service is fully developed it will become practicable to find homes in response to individual demands one at a time, but while the service is being developed it is inevitable that the agency will be acquiring a range of types of property and dealing with a number of different people. The task is therefore to match accommodation to individuals as best as possible.

In the project definition phase the upper limit in terms of number of people living together in each property will have been decided. In working within this limit the project organisers should aim to keep the numbers required to live together as small as possible and to

reduce them in subsequent schemes. The advantages of small numbers are that more properties are suitable, the home can be less crowded and the fewer people living there together with their support staff the easier it is to coordinate the smooth running of the home.

In the enthusiasm to reduce numbers, however, it is important to bear in mind the level of staff support available. The possible advantages of moving from six people in a house to four or three or two may be rendered immaterial if the minimum number of staff available at any time falls from two to one. One member of staff helping two or three people with severe handicaps means effectively one cluster of activities in one location at a time, and the constant company of other people with mental handicaps. Two staff with five or six gives the opportunity to have two quite different activities in different places and permits some individual attention to be given without ignoring other people completely. Providing concurrent activities means that they can be sequenced more flexibly and the number of people taking part can vary. The most important lower limit on size may therefore not be to do with the people served but with the smallest number of staff who can still form an effective team.

The kinds of property which will be suitable depend, just as for other people, on their appearance and siting, on the number of bedrooms, the amount of privacy and on the garden. One other consideration which is often relevant is the suitability for adaptation, particularly if a prospective resident uses a wheelchair, but also where it will be necessary to create a separate utility room or modify the stairway and hall (see Chapter 4).

Assessing the siting of a house or flat involves considering ease of access; whether there is an adequate footpath, if there are steps into the property which people living there would find difficult to use and whether it is on a main road where parking or crossing the road might be difficult. It also involves considering the location of the property among others. If it is next to or even near anything other than private dwellings there is a risk that



it will be identified as something different. Since people with mental handicaps are already at risk of being seen as different it is important to minimise the extent to which their home also draws attention to them.

Similarly, it is important to choose property that looks like a house and fits in with the neighbourhood. Property that is somehow different, either because it was built for a different purpose or because it is built in a quite different style, makes it easier for local people to mark out the people living there. A related criterion is the past history of the building: to take an obvious example, if a flat has been used by an agency resettling offenders, neighbours and local people may assume that the new residents are also offenders and negative associations may be compounded.

The remaining criteria are much more individual. If a prospective resident is noisy (if they scream for a long time each night, or play loud records or practise a musical instrument) then it probably makes sense to choose a detached house so that neighbours will have less cause to complain. For someone unable to walk up stairs, a bungalow or ground floor bedroom and bathroom may be needed. In a flat the absence of a garden may mean paying special attention to creating opportunities to use parks and public gardens. The important point about these criteria is that no blanket solution will work. It seems sometimes to be assumed that all people with mental handicaps should live in bungalows, although over 80% of children and 90% of adults can walk, or that a large secluded garden is needed when a smaller, more open suburban garden would do more to foster contact with neighbours.

In striking the right balance between individual choice and realistic necessity, the practical constraints of the housing market will constitute a powerful force. There is all the more reason therefore to pay careful attention to fostering each handicapped person's ability to choose where and with whom they live. This means employing the sort of strategies as described in Chapter 1, to make up for a past in which there were few choices to be made

and little experience of effectively making them. This is such a major choice in any person's life, however, that the most helpful thing the service can do is to provide the option of changing the decision later on.

## Routes to Acquisition

The options for acquiring property are basically to purchase (by the people who will live there, by the service agency or by a voluntary body on the agency's behalf) or to rent (from the local authority, from a housing association or from a private landlord). In the first phase of development of a service, where it is necessary to bring home many people from institutions, none of these possibilities can be ignored. It is essential to pursue an adaptive strategy of keeping all options open since no single method is likely to be free of delays and problems.

Obtaining housing for people with mental handicaps is an unusual job for a service planner. It requires a thorough understanding of the needs of the people to be served and of the philosophy underpinning the provision in order to discriminate the desirable from the undesirable. At the same time, it involves a good deal of low-level practical work (such as visiting estate agents every week) to make sure the job gets done efficiently. Some project organisers might feel that these kinds of tasks should not fall to them; they may even have a problem justifying why they are spending their valuable time in such menial pursuits. However, these tasks need to be done and done well if more time is not to be eventually wasted pursuing possible sites which are doubtful from the start or in trying to remedy obvious design faults.

Whatever route of property acquisition is being used, the technical staff of the agency and the local authority responsible for architectural and building services, advice on fire regulations and costs, will be heavily involved. Since these people may exert a major influence on the



scheme, and they will not know the aims of the project, the rationales for the decisions being made by project organisers or the precise requirements of the project, they must be brought into the project at an early stage and their support must be enlisted. The idea of staffed housing is still relatively novel and easily misunderstood, and these staff will have well worked-out ways of doing things which may need to be modified.

This need can be addressed in part by giving people a clear statement of what is wanted and why. But it is also to do with respecting people's carefully guarded area of responsibility - not seeming to want to ignore or bypass people - and with socialising the individuals concerned into the team of people fighting for better services. Some of the suggestions made later in this chapter in relation to neighbours could be used with advisers and technical staff.

Sometimes it will not be possible to gain the confidence of an important decision-maker, particularly where the tradition of giving extremely cautious advice to avoid any possible comeback is well-established. In these circumstances it is appropriate to raise the issue at a more senior level as both a matter of principle and in terms of deciding accountability for the people who will suffer the consequences of a wrong decision.

Given the scale of the task, it is probably useful to try to establish a task force model of work, in which the same group of project organisers and technical staff see all property, so that a common core of accepted ideas and expertise is quickly built up. It is essential to be able to handle a range of possible schemes at once, reaching quick decisions on absolute non-starters and moving fast to acquire good homes. The aim is to match the speed with which ordinary members of the public act in trying to acquire a desirable home.

*Purchasing Property*

There are two advantages to purchasing housing: the ownership of the property is straightforward and no other agency has a claim on it, and the property will almost certainly increase in value at more than the rate of inflation. These advantages, together with the financial incentives available to purchasers, make home ownership a valued option for many people.

It may sometimes be possible and desirable to help people who need essentially 24-hour staff support to purchase their own home, using their own monies or a grant from the service or elsewhere to provide the deposit, and sharing mortgage payments met from social security payments. This depends on who will act for the individuals concerned in a legal sense and how the service agency can be sure of protecting the rights of the occupiers.

The common alternative is for the service agency to buy property to provide a home for individuals or a few people living together. There are however pitfalls in a statutory authority providing property in this way, both in terms of the acceptability of the end product and the time it takes to complete the purchase.

It can be very difficult to get a service agency to provide domestic housing. Social services departments and district or regional health authorities have no significant history of providing ordinary housing and their procedures and expectations are geared towards relatively large, long-term capital projects in which there is a risk of losing money. They are ill-equipped to operate in a market characterised by active competition for attractive houses where there is much less risk of losing on a transaction. The administrative procedures for authorising purchase are usually cumbersome and slow, and it is difficult to retain control over the architectural, engineering and design issues being decided. The orientation of the technical staff involved may make them unsympathetic to finding ordinary domestic-scale design solutions and they will have worked in an environment



where rather more weight is given to professional views and the avoidance of subsequent blame than to the needs of the service consumer.

Thus, the agency may fail to acquire suitable property, either by relying on formal notification rather than active searching (thus losing the property which is most saleable), or by relying on technical staff who have implicit criteria which rule out most available housing (assuming, for example, that only bungalows should be purchased when the project organisers envisage a range of property types).

To find good homes, the project organisers will have to spend time touring the prospective areas looking for them and visiting estate agents to demonstrate continued interest. Local supporters may be able to help in this, but it is most unlikely that it can be done from an office desk. However clearly estate agents are told that ordinary housing is required in centres of population, and that price is much less of an issue than location, their own prejudices and beliefs will make them select out properties they consider suitable - large, in the countryside, unlikely to attract other buyers.

Having found a suitable house or flat, the agency may still lose the property by inadvertently abusing the seller's goodwill. The sequence of events and the point at which a purchase is confirmed is different when a public authority buys property than when the buyer is an ordinary citizen. Failure to explain these differences can mean that the agency's firm intention to purchase is not realised or believed by the seller.

Typically, the agency expresses an interest to the seller and arranges for a succession of staff to visit to carry out an appraisal, perhaps with the prospective residents or their families, to complete a structural survey and, if necessary, to prepare conversion plans. The District Valuer will be asked to set an upper limit on the value of the property and cost estimates are put to the relevant agency committee for approval. Meanwhile, change of use planning permission may be sought from the local

authority. Only at the end of this process can the agency agree the price and complete the purchase.

Thus, for the person selling property to a service agency, there is a period of uncertainty which may last several weeks after the initial contact. Dealing with a private purchaser is quite different; a firm offer is made and accepted within a few days. There is a similar period of uncertainty while the prospective purchaser carries out a survey, conducts necessary legal searches and arranges a mortgage, but the offer 'subject to contract' appears to give greater security. It is essential, therefore, to explain all this to the person selling the house and to maintain frequent contact by telephone during the period of uncertainty. At the same time, the project organisers have to impose a continuing high level of demand on the technical staff concerned to get their job done in the fastest time.

Even if it successfully purchases an ordinary house or flat, the process of conversion and adaptation by the service agency may substantially and detrimentally alter its appearance, and thereby the perception formed of its function by local people, visitors, staff and indeed the people who live there. It is quite possible to turn a private house into a building that everyone perceives as an institution of some kind.

If this is a serious risk, then one alternative to trying to influence the agency is to try to use a different route for property acquisition by, for example, setting up a charity to purchase and own property for the project. This is unlikely to make any difference to the kind of adaptation needed (whatever regulations are involved will still apply) but it may speed up acquisition and it may allow the use of staff and procedures more geared to providing homes for people. Probably the most widely used way of doing this is to collaborate with a housing association, which is discussed below.

Finally, it is necessary to decide on the status of the people who will live in the property provided by the agency. There are three options: they can be inmates or patients, they can be tenants or they can be licensees. The



status of inmate or patient is that of everyone in local authority residential care or in hospital: the individual has no security of tenure and no formal say over their living arrangements (their furniture, who they live with, what time they have dinner and so on), although the service agency can make various commitments in these areas as a matter of its policy.

At the other extreme, the agency can rent property to the people it serves as tenants. This gives them many more rights including the possibility of purchase in some cases and certainly the right to refuse to have staff on the premises. Although this might make a neat reversal of roles in terms of authority, it will pose serious problems where one member of a group refuses access when care staff are concerned about the possible exploitation or neglect of others.

As an alternative to tenancy, each person can be a licensee. This type of agreement is widely used with students and compromises between the individual's rights to live in their own way secure in a home of their own and the needs of the service to monitor the quality of care it offers and to shape the development of the service. Since rules about these options change, it is essential to get up-to-date guidance in order to find the least restrictive alternative for the people served.

### *Renting Property*

Since social services and health agencies have such difficulty providing ordinary housing, a logical alternative to purchase is to rent. This leaves property acquisition and management in the hands of a specialist agency like a housing department or housing association, or a private landlord, so that the service agency can concentrate on the organisation and delivery of staff support. The advantage sought by this arrangement is that the housing agency will be more skilled purchasers and better managers of property: an empirical issue worth further study. It may also be the case that conversion and

renovation costs are kept in greater check when specialists are used.

A second advantage of rental is that it can be more flexible than purchase so that, as needs change, property can be more easily relinquished and new accommodation acquired. This potential advantage is, however, less important in Britain where the size of the rented housing sector is small and shrinking.

One direct route to finding a home is to rent property from the public housing stock of the local authority housing department, either simply by placing the names of the potential residents on the waiting list or by negotiating a policy of positive discrimination in which a proportion of houses are set aside for people with mental handicaps. In this case it is important to appraise the housing department of the philosophy and requirements of the project to avoid their offering a series of unsuitable properties which are then turned down. In some areas it has been common practice to build public housing estates with few amenities in relatively inaccessible parts of town, so that whole areas may be unsuitable on location and siting grounds. Similarly, some departments group disadvantaged people in particular areas and may offer homes there as a first option.

A variation of this approach is for the service agency to provide funding for a housing department to purchase property which they then manage as part of their housing stock, as in the NIMROD service in Cardiff. Although this may be an attractive option for the service agency, one factor which needs careful consideration is how the rent is calculated. Although, if people share a house, this can reduce the rent payable by each person, the recovery of loan charges through the rent can raise payments to a level where other options might be more attractive. In the NIMROD service (as reported in 1983) the rent varied according to the number of people occupying each house and the loan charges on capital. In total, rental receipts for each property ranged from about £120 to £160 per week. This was considerably more than the ordinary



council housing rent in Cardiff and was greater than the payments for a 100% mortgage on many ordinary houses.

In the NIMROD service these costs were met from social security because the people served were able to claim ordinary housing and social benefits. For a service agency working within cash limits this may represent an additional source of finance for the housing programme, although it may represent the same or greater cost to the nation as agency purchase.

Collaboration with housing associations is another major route by which homes can be acquired for people with mental handicaps. Housing associations are voluntary bodies which can receive capital and revenue grants to enable them to provide and manage housing, either for ordinary people or for people in priority groups.

There are three sources of capital available to housing associations: housing association grants from the Housing Corporation, access to loan finance via local housing departments and health service grants. The first two routes were designed for housing people needing limited support from staff. The staff:client ratio must normally be less than one established staff post to 2.5 people served and the Housing Corporation will not give capital grants for 'high care' schemes. In practice it may be possible to circumvent the staff ratio requirement if extra staff can be seen as peripatetic visiting staff rather than as allocated to a single property or scheme. Capital from these sources also requires that the scheme is managed by the housing association or a voluntary agency rather than the social services or health department.

These restrictions do not apply where the funding source is a grant from the health service. This can either be from joint finance or from the ordinary pool of resources, using the provisions of the Health and Social Services and Social Security Adjudications Act 1983 to transfer National Health Service resources to social services departments, housing or education departments, to the Housing Corporation or to housing associations, for duties under specified Acts of Parliament and as long as

the expenditure has been agreed by a Joint Consultative Committee.

Revenue to run a service using housing association property can also come from three sources: charges made to residents, deficit funding from the Department of the Environment or "topping up" money from service agencies. Deficit funding is most likely where the scheme is considered as a 'hostel', which means it must be providing more than six places (although not necessarily on the same site) and there must be an element of shared living. The 'hostel deficit grant' will not, however, cover the costs of a heavily-staffed scheme and some "topping up" finance will be needed. This can come from social services, health or voluntary agencies. The only important restriction appears to be that, where the extra costs due to the need for staff support are more than five times the usual management costs, the scheme can be considered 'high care' and therefore ineligible for Housing Corporation capital support. Where the capital is obtained from the health service revenue can be "topped up" as required.

## Public Relations

Opposition from local people is often cited as a major obstacle to the development of staffed housing in the community. The rest of this Chapter is devoted to effectively managing the public relations of a staffed housing scheme with local people.

It seems sometimes to be assumed by service agency staff that hostile public opinion is entirely irrational and based on prejudice and ignorance. In so far as this is the case, rational argument will be a weak remedy and conflict the likely outcome. A successful strategy depends on a rather more sophisticated model of local opinion.

First, it is important to recognise that almost everyone wants to find out about their prospective neighbours, not least because of the opportunity neighbours have for disturbing established ways of doing things. It is therefore



quite natural and sensible for neighbours to talk to the person selling or renting their house about potential residents.

Second, there are many legitimate concerns neighbours can have. Issues like noise, privacy, car parking and the number of people coming and going often have an impact on neighbours and, although they may have no alternative but to put up with whatever happens, they can expect (and in some cases even require) a reasonable kind of behaviour.

Third, the negative predictions neighbours may make are also often rational appraisals based on good experience. Not all these predictions or assumptions are about people with mental handicaps; some are about public service agencies and the professionals who work for them. If people believe that public bodies often conceal their true intentions, execute their plans incompetently, incompletely or very slowly, cause unnecessary distress, behave insensitively, change their minds without telling anyone and let standards slip over time, perhaps project organisers need to convince themselves that this time it will be different before trying to convince local people.

Managing public relations effectively depends on teasing out these different issues so that reasonable accommodation can be made to legitimate practical concerns while holding fast to issues of principle. It is important to enter into the whole process on the basis of informing people about firm intentions as a courtesy to them rather than in any sense of asking their permission. This requires that the agency has some firm intentions - there is no easier way to unsettle people or provoke objections than to be muddled or tentative about issues like who will be served or how much support they can be guaranteed. It is also not much use if the clear vision the agency has is kept to itself or wrapped in jargon; clarity and consistency from everyone who might be asked is essential to counteract the inevitable rumour and uncertainty.

Finally it is important to take a medium-term perspective on the issue of public relations. Every time the service agency attempts to secure property it is setting up a learning experience for local people - not so much about people with mental handicaps, although that is true too, but about its sincerity, commitment and competence. If the agency refuses to be turned aside, if it fights every case as far as it can, if it mobilises support against opposition, if it knows what it is doing, if it sets up good services, then over a few years people will be less likely to oppose its plans (both because they will have fewer fears and because they will predict less chance of success for opposition).

*Meeting the Neighbours*

The neighbours will soon find out that the prospective purchasers or tenants are a service agency acting for some people with mental handicaps. Three objectives can be achieved by meeting the neighbours at the outset. These are first to provide them with an accurate account they can reflect on, tell to each other and to people who ask them about what is happening; second to gain their commitment to the project before an opposed lobby forms and third to establish a direct route by which their satisfaction with their potential new neighbours can be monitored. These objectives apply also to the person selling or renting the property and the suggestions that follow are also relevant for them. If the service agency does not take responsibility for immediately talking to the neighbours, the existing owner is put in the position of having to examine their conscience as to what to tell neighbours.

The first step is to meet the neighbours as soon as the vendor has been told of the service agency's interest. Only two or three people should do this and they should call at the door of the immediate neighbours of the property, including those whose gardens back onto the premises. If people are out, the visitors should call back later the same



day or the next day. They should explain that they are thinking of buying the house and would like to talk to the neighbours, offering to come back again if they have called at an inconvenient time. Since the aim is to develop an individual commitment, neighbours should if possible be seen in their own homes on their own and only immediate neighbours should be included. Public meetings should be avoided if at all possible (see below).

The people visiting neighbours should include someone who can answer all the practical questions about the service people may have, plus someone who will be seen as sufficiently senior that their expressions of good faith will be believed and someone who can speak for the prospective residents. This can either be a resident or an advocate but a powerful member of the group could often be a parent or relative - someone who lives locally, who will be seen as having proxy rights of residence and who is not identified with the professional staff of the service.

The neighbours should be given a clear explanation of the service agency's intention, focused around the individual handicapped people themselves and making use of photographs of the people and the importance of bringing them back to their family and neighbourhood. A major strength of the presentation is the local basis of the service, 'bringing people back home', and the appeal to the community to support its most disabled members. Opposition is much more effective if the proposal can be represented as the arbitrary hand of bureaucracy 'picking on' innocent local people. It will help if a short, well-prepared written statement can be left to serve as a reminder of the key issues later. The problems people face should be explained in a matter-of-fact way together with the way the service is set up to meet them (a brief review of the feasibility of this kind of service). Give particular emphasis to the fact that the service is a housing service and does not also provide an advice centre, day care or out-patient clinic, and there will therefore be no more coming and going than in an ordinary house. Even if staff duty times are not worked

out, give some indication of the number of staff who will be arriving and leaving with approximate times.

The neighbour should be afforded as much opportunity as they need to ask questions and express any fears they may have. The people representing the project should firstly give clear answers wherever they can, secondly distinguish between issues where they can compromise and those where they cannot and - most important - thirdly should remember any undertakings they give at this point and ensure that they are acted upon. Finally, they should leave the name, address and telephone number of one person the neighbour can be advised to contact if they are concerned about anything at all.

It may be relevant at the first meeting with the neighbours to discuss the likely relationship they will have with the future residents. Just as with anyone else, this will be what people choose to make of it. Although project organisers may expect opposition, at least some neighbours may want to help and ask for guidance. In these circumstances it will help if members of the project team have worked through the issues about voluntary help and are able to talk to the neighbours who envisage becoming involved with this general policy in mind.

Whatever shape the relationship with the neighbours takes it is important to remember that it starts with the first visit and it will grow with repeated contacts. Having made the initial contact, the project organisers should stay in touch, checking discreetly and regularly that the neighbours are satisfied with the behaviour of the agency. If it is not possible to discuss the way the property may be altered externally at the first visit a second set of visits to neighbours will be needed so that they are kept informed of the way the developing service will affect them. At this stage the prospective residents are not really likely to be involved at all: a much more common focus of concern is the extent to which the agency looks after the property while it is being converted, how well the garden is kept, whether informal rules about where people park their cars are being violated and so on.



*Obtaining Planning Permission*

Two kinds of planning permission are commonly involved in developing staffed housing for mentally handicapped people: planning permission for change of use gives permission for a private dwelling to be used as a service setting; planning permission for adaptation is required to convert the property and ensures that the conversion meets local planning requirements and building regulations.

Planning permission for change of use is not needed by private individuals taking over a private dwelling to use as their home, whether they are related to each other or not. Whether planning permission is required for staffed housing is likely to depend, therefore, on whether the planning authority accepts that the house is just like a private home. There is a specific use class in the Town and Country Planning (Use Classes) Order, 1972 for "a home or institution providing for the boarding, care and maintenance of children, old people or persons under disability". For schemes which claim to be for groups of single people living as a household, receiving whatever levels of staff support, planning decisions are often inconsistent and there is an acknowledged need for reform.

This is a familiar picture in dealing with official regulations. Although the local planning staff concerned might believe they are applying clear rules and regulations almost without interpretation, their decision is in fact likely to be strongly influenced by local circumstances, their beliefs and the history of policy in their authority.

At the first review to identify possible neighbourhoods in which to acquire property, the project organisers should meet staff in the planning department and talk to them about the new service. In particular, it is useful to explain the territorial planning basis that underpins the entire programme so that the planning department can assess how carefully a reasonable balance in the distribution of services has been created. They can also

see the extent of the job so they know how much the community is being asked to accept.

At this point it should become clear whether some or all of the types of housing to be provided would need change-of-use planning permission. The issues the planning officer will take into account in making this decision are the ownership of the property (agency ownership predisposing against the property being accepted as a private dwelling), the status of the residents (inmate status going against), the number of residents (larger numbers going against), the way people live (if they play no part in running the home or live as multiple occupants this will go against), the number and allocation of staff (high levels of staff always on the premises going against) and the formal status of the scheme. If it is a registered home or is classified in Group 2 of the Building Regulations - see Chapter 4 - it is more likely to be seen as needing change of use permission.

This informal consultation to win over the planning staff is backed up by a formal opportunity under the Planning Act, 1971 to apply to the local authority for a legal opinion on the need to seek planning permission. This can be followed by appeal to the Department of the Environment. One other relevant point is that, if the property is owned by the Crown (for example, by a health authority), planning permission is not required. In practice most District Health Authorities will seek and be bound by the planning authority's view, but this does provide one possible way of dealing with a difficult planning authority.

One unfortunate side-effect of needing to ask for change-of-use planning permission is that a house whose future function the service agency has chosen not to advertise will be so advertised. Typically, notice of planning applications has to be given in the local press and in public places (noticeboards are often attached to lamp-posts). In practice these do not seem to be the major source of community reaction. If there is to be an adverse reaction it is more likely to come from people in the local area who hear of the possibility of the service being



located near them from the present owner of the house or flat, or from contacts in the planning department. These can best be forestalled by effective liaison with immediate neighbours and with planning officials.

Once planning permission has been applied for it is useful to maintain discreet contact with the planning department who may be able to give advance notice of issues likely to be raised at the council meeting. This meeting should be attended by representatives of the project and relatives of the people to be served. Even if there is no opportunity to speak to committee members before the meeting the presence of supporters indicates the seriousness with which the agency views its commitment and allows the representatives to hear the arguments used for and against the application at first hand.

If the application fails, appeal. Permission can only be denied on *planning* grounds, although committee members may have difficulty distinguishing planning grounds from their views about the prospective residents. If a negative decision is based on apparent prejudice or clearly mistaken ideas about the service the chances of successfully appealing against it are quite good.

### *Responding to an Organised Lobby*

Sometimes local circumstances will conspire to generate concerted opposition to a particular scheme. The response to a hostile lobby requires two strategies: control of the network of rumour, accusation and counter-accusation so that the dispute is, as far as possible, localised; and presentation of a creditable case defending the rights of people with mental handicaps to the protestors, either individually or in a group.

The first step is to evaluate the complaints of the people protesting: if they have correctly identified weaknesses in the service proposal, change the proposal before defending it in public. If done well, this can make the difference between a humiliating climb-down which

demonstrates that the service agency is incompetent and a helpful accommodation to local feeling which preserves the agency's principled commitment to people's rights.

The second step is to ensure that every potential spokesman for the scheme is telling the same, accurate story. This is not just a question of agency staff; opposition may elicit support from other public organisations (churches, parents' groups, social clubs) whose spokesmen may not know the details of the proposal or accept or understand the principles on which it is built. Two examples from experience illustrate the potential problem: in one, a spokesman offered the justification that the service was only needed for the current generation of people with mental handicaps, since advances in medical science would remove the need for residential care by prevention or abortion; in the other, it was claimed that people would never leave the house and so could not be a nuisance to other people. Any novel project can do without this kind of help.

Having prepared the organisation in this way, the agency is ready to respond to the objectors. The first choice should probably be to carry out the kind of individual visit described for immediate neighbours. If this is not possible it may be necessary to respond in the media (if that is where the complaints are being voiced) or in a public meeting.

Public meetings are an unhelpful format in which to hold rational discussion and they are probably best avoided. If they must be held, it is important that they are convened either by the service agency (when it has its case best prepared) or by a genuinely neutral body. The worst scenario is a meeting called by a partisan group at too short notice, chaired by someone unable to manage the high tensions generated.

Make sure articulate and moderate supporters are present at the meeting. Talk accurately and honestly about the problems and strengths of the people to be served; illustrate the points made with slides of good services for people with similar disabilities. Invite neighbours of other schemes to speak, if they are willing. It may be



appropriate for relatives to speak (so that it becomes more clear that people are attacking local families by their opposition), although it is important in a public meeting to avoid seeming to put the handicapped individuals and their families on trial. Distinguish the problems of the individuals to be served by this scheme from those of other handicapped or disadvantaged groups. Make sure the local press are well briefed of the facts of the service proposal and give them a number of short statements that they can use to describe the content of the presentation.

Remain calm at the meeting and avoid attacking the most vocal objectors in the audience. People may say outrageous and completely untrue things. These statements often discredit the speaker and serve to drive some protestors to disassociate themselves from what they see as an unreasonable extremism. Finally, show confidence that the objectors are reasonable people who are misinformed and are capable of changing their views. For those who obviously do not fall into this category, make clear that the agency could, if it chose, force and win a planning enquiry. Above all, end the meeting only when all questions and opinions have had an opportunity to be heard and without compromising on the agency's commitment to go ahead.

Once opposition has been articulated this clearly, the project organisers may feel they face a dilemma about whether to proceed. If they give in they make it harder the next time; if they go ahead they risk exposing the people they serve to unpleasantness and exclusion. There is some evidence that any initial difficulty is short-lived, and this may predispose towards going ahead where the main source of opposition is not from immediate neighbours but from opinion leaders who are less likely to meet the new residents. One consequence of pursuing a number of potential properties at any time, however, is that it does give the option of discarding property in a really hostile location. Even then, it may be worth postponing this decision until after winning an enquiry. It is certainly desirable to maintain the impression that the

service is prepared to fight against opposition in order to protect the rights of people with mental handicaps.

## Further Reading

Preparation of parts of this chapter was greatly helped by an excellent review of sources of funding for housing projects in the community prepared by Chris Heginbotham for Centre on Environment for the Handicapped and referred to below.

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# 4. Design

Design issues arise in staffed housing for two reasons: first, regulations governing fire safety, environmental health and some planning requirements intrude upon the housing of people with mental handicaps because of the involvement of service agencies; and second, most agencies making this kind of provision have centralised or bulk purchasing arrangements and expect handicapped people to fit in with these when it comes to furnishing and equipping their home.

The main objective in housing design and furnishing is, therefore, the extent to which the people planning the embryo staffed housing service can push as much decision-making and control down the line to the service consumers, so that people can choose their own spaces and furnishings. For any particular project a compromise will be made between personal control and service constraints; but it is important to press ahead to achieve a more imaginative agreement next time, so that obstacles that prevent people living in attractive, well-sited housing among personally chosen furnishings and possessions are constantly exposed to critical scrutiny and pressure. Only in this way will the 'rules' ever be changed to meet people's needs.

Compromises between personal choice and service constraint are compromises between official bureaucracy and the rights of the individual, not between high and low standards. For example, the problem with fire precautions is not that people promoting staffed housing should be indifferent to fire risks, but that the scale and interpretation of what is required so often extends beyond what is reasonable, introducing major penalties in other areas of people's lives.

The effect of compromises can be minimised if they can be changed later. It may not be possible or desirable to involve the people who will live there in choosing decor and furnishings for a staffed flat before they arrive - they may be in institutions a long way away, or they may not yet have any basis for making these kinds of choices. The appropriate service response may therefore be to provide attractive decor and the minimum furnishings needed to start up the home (leaving everything possible for people to buy in their first months of residence). However it is important to plan for the early replacement of what has been provided by personally chosen materials.

Acceptance that, for any one project a compromise is being made, is not a reason to accept unattractive, intrusive or second-best solutions. Although the first choice will usually be for the people served to decide as much as possible for themselves, high standards can still be met where regulations apply. It is possible to achieve attractive, age-appropriate design, furnishing and decor and still satisfy fire safety advisers and (if absolutely necessary) to use central supplies to do so.

Choice is not the only goal. The design and furnishing of a home are an important social commentary on the people who live there and ensuring that the home gives an impression of competent, skilled people with good taste and the other social virtues means attending to aesthetics and age-appropriateness as well as to personal choice. There will often be tension between the kinds of choices people would make and and achieving attractive, status-enhancing possessions. Guidance to avoid damaging choices, support in a range of experiences to broaden the knowledge base on which people make their decisions and help in making choices is just as much a part of design and furnishing as it is part of other areas of a service for people with severe or profound mental handicap.

### *Architectural Ideology*

Perhaps it is also necessary to stress that there is no empirical basis for designing elaborately different, special living environments for people with mental handicaps. People may have physical handicaps which have to be

taken account of in adapting their house, but this is an individualised response to people's needs. Institutions are littered with bizarre architectural features included either because people thought they would help mentally handicapped people or because they reflect unconscious assumptions about people: colour-coded stripes on walls to 'help people find their way around'; extensive aids and appliances for people with physical handicaps; fountains in living-rooms, unevenly-sloping floors, walls and ceilings sloping at unusual angles.

Very often, these ideas reflect the planner's attempts to design away problems caused by the existence of the institution. So extra guidance (stripes on the walls) is needed around buildings which are large, impersonal and have many similar spaces; every imaginable aid for disabled people has to be built in if the building will be used by all sorts of people with different disabilities instead of by a few; exotic interiors are included to make up for the barrenness of people's lives and the poverty of ordinary experiences in the environment.

Sometimes unusual solutions are proposed on the basis of trying to design away problems the people who live in the home may have, such as incontinence or problem behaviour. All too quickly this becomes the rationale for providing barren, lowest-common-denominator environments designed to be indestructible. The appropriate response to these kinds of problems is largely made up of what staff do and how well they are organised and trained. Some risk of damage may have to be tolerated (and budgeted for) rather than deliberately impair the quality of the living environment. Special design solutions should only be adopted as an individualised response at a particular point in time, which satisfies ethical concerns about the 'least restrictive alternative'.



**Room Layout and Adaptation**

Some idea of the range of workable room layout options is needed in order to evaluate potential properties. Similarly, where adaptation and conversion is needed to provide for a resident with a mobility handicap or to meet fire regulations, some properties can be ruled out at first sight because the changes needed would destroy too much garden or render existing rooms unusable or because they would impair the appearance of the property in ways which would mark it out in the neighbourhood.

The criteria for the basic layout of the accommodation are essentially the same as for any private dwelling: attractiveness, convenience and flexibility. Additional criteria arise from four sources. The first of these is where the accommodation is for someone with a mobility handicap and it is necessary to consider their access to the building and to different rooms. Secondly, where several people are living together, there are some options about communal living areas and, where a high level of staff support is involved, about space for staff functions like writing and keeping records. The third source of criteria for basic room layout is fire safety advice about means of escape and control of the spread of smoke and fire in the building. Finally the placing of the kitchen and utility areas may entail attending to the advice of an environmental health specialist in cases where this is thought relevant.

*Accommodation for People with Physical Handicaps*

There is now a wide range of sources of advice about accommodation for people with mobility handicaps. The most important general point for a service agency developing staffed housing for mentally handicapped people, some of whom will have mobility handicaps, is that the practical problems people will encounter depend on individual factors. There is no point in trying to adopt universal solutions which make every disabled person fit

into standard arrangements. The different nature of the handicapping condition, the person's strength, stamina and weight and the kind of aids they use will all have some influence on their accommodation needs.

Access to the building is the first practical issue. If any adaptation is necessary, the aim should be to provide access at the ordinary entrance door to the house or flat. Where several people live together, providing an accessible second entrance (making a person in a wheelchair use the back door) means that when they are out with another resident and a member of staff either they will all use the second entrance or the group will split at the front door, requiring staff to be particularly well-organised to receive the people arriving (assuming they need this much help).

The second issue is where a person with mobility problems will have their bedroom and bathroom in a property with more than one floor. The options are to provide a lift (either a stair-lift or a shaft lift) or to convert or build on ground floor accommodation. The main arguments against lifts are the space they take up, their unreliability and whether they can be used in the event of fire. These are problems readily amenable to technological solutions and it is important to take up-to-date advice before assuming that lifts cannot be used.

Converting rooms on the ground floor introduces a different problem in that it distorts the space distribution between ground and upper floors. Most houses have the same floor area on each level, and relocating a bedroom and bathroom downstairs is likely to create a shortage of rooms for communal use on the ground floor. In older properties with three living rooms and a kitchen, it may be possible to convert one of the living rooms to a bedroom and to build a small extension for a bathroom.

Often it will be necessary to consider a ground floor extension to add a bedroom and bathroom at the back or side of the house. This not only has implications for the amount of usable garden which will be left, but also for loss of light in the room from which the extension is made. In terms of the amount of space required, it seems



to be generally the case that Department of Health and Social Security cost limits on new building are too restrictive, probably because they are calculated on the assumption of communal facilities for groups of people. This is likely to present a problem in providing a bedroom large enough for an adult using a large wheelchair (such as a powered chair with computer-aided guidance) and in the bathroom.

Many care staff and professional advisers argue strongly that a large person who needs help to get in and out of the bath should have the bath free-standing (a 'peninsular' or 'island' bath) so that a member of staff can get down each side of the bath to assist the person in and out without risking injuring themselves. This takes a great deal of space which may not be available, especially if the bathroom also has to include a toilet with space for the individual to transfer from the side, rather than from the front.

The alternative is to provide either a mobile or fixed hoist. It seems that the kind of designs of hoist often used in residential facilities take so long to set up that staff often do not use them. The person in the hoist may also feel insecure. As with lift design, these are problems which could easily be solved by the application of imaginative design and manufacturing skills and it is important to look for the most up-to-date solutions available at the time. Since the provision of aids for disabled people in Britain seems tainted with the idea that people should make do with cheap, heavy, inelegant and out-of-date equipment the project organisers may have to fight for aids that maximise an individual's independence.

The final issue to consider in room layout and adaptation is whether the width of doorways will need to be increased to permit access by people using wheelchairs. This depends on whether people are using bulky wheelchairs and on whether they propel themselves by hand as well as on how wide the doorways are.

*Sharing and Comnzunal Spaces*

Where several people live together with staff support there is a basic choice between living as a single household and living as separate individuals. In the former case, the property needs to provide communal areas (living room, dining room, kitchen etc.) large enough for the household as well as enough bedrooms. If people are to live separately, less communal space is needed if the property is designed as a number of more-or-less self-contained bed-sitting rooms or flats. Which of these choices to opt for depends on the individual needs and preferences of the people concerned although, if people have such different needs or interests that living separately is the sensible choice, it may be more appropriate to seek several flats near to each other rather than congregate everyone on the one site.

The kind of property available, and the resources the agency is prepared to commit towards staffing levels, impinge on whether people will be required to share bedrooms other than when this is their clear choice. Providing everyone with the choice of a single room is a desirable goal but may take time to achieve. It is necessary to consider carefully whether, if it means fewer people being housed or taking much longer to get people out of poor quality services, insisting on single rooms from the outset is worth it. For people who have lived with 20 or 30 others for years a room shared with one other person may be preferable to a long wait. In these circumstances compromising on people sharing rooms at the beginning can be redressed as the service develops, using the improved quality of life experienced by individuals in the new service to justify more accommodation to those who allocate funds,

Another set of constraints on overall design of a house or flat is the provision made for staff. Traditionally, staff working in residential care facilities could often expect an office, a rest room or a meeting room and segregated dining, toilet and cloakroom facilities. It may be tempting to sweep all these aside in moving to a model of care based on supporting people in staffed housing, but at least some of the needs met by this provision still exist in housing services.

Staff working with severely and profoundly mentally handicapped people in a high-quality service will be using quite detailed records of individual progress and the quality of the setting. These records need storing and staff need somewhere they can spend time consulting and amending them (working out the next step of a teaching strategy, for example). Staff also need access to a telephone, and there needs to be somewhere safe to store money, medicines and the personal belongings of staff while they are on site.

One way of doing this is to provide an office base near where people live and expect staff to work from this office, visiting people in their homes only to work directly with them. All that would be provided in each home is safe storage. This model could work quite well, for example, in providing staff support to several flats in adjacent blocks. It is less likely to work well where, even when staff are preparing teaching programmes or keeping records up-to-date, they are used to give minimal supervision or 'cover' for some people in the house or flat. If, for example, two staff are available to work with four severely or profoundly mentally handicapped people the most effective way to work may be to fit in at least some record-keeping around resident activities rather than send one staff member away to an administrative base.

A second alternative is to provide discreet storage in the house or flat and for staff to use the dining room table to work at instead of a desk. Paper records can be kept in a drawer or bureau, medicines in a locked cabinet in the bathroom and money in a *small* safe. The main disadvantage of this is that visitors see staff doing paperwork in what is intended to be a home, and that mixing up a staff function with the home may give staff the idea that really they own the space.

Another option is, therefore, to provide separate facilities on the premises such as an office or study area. Although this avoids staff taking over living space to do

paperwork, it does create the risk of staff spending time in a comfortable office away from the people they are supposed to serve. It also creates another room for which space has to be found. If an office is to be provided, it should be small, furnished as a place for working rather than as a rest room, it should occupy the least useful space in the property; an attic room is ideal, or part of a large upstairs landing - not what should be the main sitting room downstairs. The operational policy should make clear first, that it is not a private space for staff - if residents wish to use it they can - and second, that it is a study area not a rest room, since staff are required to take their breaks and meals with the people they serve.

It is much easier to decide that other kinds of segregated facility should be avoided. Sitting rooms, dining rooms, cloakrooms and toilets should be attractive enough that staff are as ready to use them as they expect residents to be. If personal property of staff goes missing then *everyorte* needs secure cloakroom facilities, not just staff.

*Fire Safety: Relevance of Guidance*

Much energy among people developing staffed housing for mentally handicapped people is spent debating whether houses should be subject to the fire safety provisions of the Building Regulations and subsequent government guidance relating to residential homes. The Building Regulations define different 'purpose groups' of accommodation. Group 1 consists only of private dwelling houses; every type of residential or nursing home or institution or hospital is lumped together in Group 2 (other groups deal with commercial premises). It is this unimaginative lumping together of widely differing residential facilities in Group 2 that leads to problems, since the fire safety guidance issued for this Group are usually formulated with large residential homes in mind. The desire to avoid silly, obtrusive impediments leads



people to argue that staffed housing should really be considered as Group 1.

It may be possible to convince the fire safety adviser of the service agency concerned (who will certainly take the advice of the local fire brigade) that a housing development is Group 1 if some or all of the following conditions are satisfied:

1. the people living in the house are the tenants or owner-occupiers
2. the staff who support them can be represented as domiciliary visiting staff spending longer than usual in the home (like the home night nursing service, for example)
3. the house is furnished as a private dwelling (i.e. it does not have an office etc.)
4. the house is not registered under any legislation

Setting up houses along these lines may overcome the worst excesses of current guidance, but these are two obvious drawbacks to this approach. First, fire safety in private dwellings is appalling and the project organisers should consider seriously whether they want to expose the people served to this degree of risk (even assuming that the agency will be prepared to accept it). Second, if providing unregistered housing is the route chosen, a judgment has to be made about how long it is likely to be before registration is required (especially if this method of avoiding fire safety advice is more widely adopted).

If the houses and flats provided are to be classified as Group 2, the task becomes one of achieving a balance between fire safety and maintaining the appearance of the home and its fitness for enabling people to live good quality lives. Probably the most important intervention to achieve this goal is to secure the interest of the fire safety adviser and their commitment to the philosophy guiding the project. Part of this process should be arranging clear indications from chief officers that they are committed to this philosophy and its implications as well. so that the

fire safety adviser feels supported in finding imaginative solutions to design problems.

It is particularly important not to muddle up two different issues: which is the appropriate purpose group and how to get a good solution within Group 2. If the project organisers keep returning to the first question they may inadvertently give the impression that their aim is to avoid reasonable fire precautions. In dealing with fire safety advisers it is essential to demonstrate commitment to achieving proper safety standards and to make clear that the area of debate is how to do this without sacrificing the quality of life of the people served.

The main source of guidance likely to be used by a fire safety adviser is the Home Office *Draft guide to fire precautions in existing residential care premises* published in 1983. Although a draft guide this document represents substantive guidance - it is only 'draft' in the sense that it does not have the statutory force of the 1971 Fire Precautions Act. Although it refers to existing premises, the Department of Health and Social Security advises that it should be used in planning new buildings as well, in the absence of any other guidance.

The main body of the *Guide* is written as if for a large, institutional establishment and would, if taken at face value, predispose towards ugly, intrusive fire precautions. However the introduction to the *Guide* does say that both advice given and action taken should take notice of the fact that the *Guide* does not have statutory force and that

1. "It is intended to be used as an indication of the general standard to be aimed for rather than as a set of measures to be rigidly applied in detail in all circumstances."

2. "It is important that ... consideration should be given to ... the limitations of adapted accommodation, the physical and mental capabilities of the residents and the staffing levels and degree of supervision day and night."



3. the need for fire precautions is to be "carefully weighed" against the need to maintain a homely and non-institutional atmosphere.

The main impact of fire safety advice in terms of accepting or rejecting particular properties is in providing a means of escape from every part of the building. The following section discusses the objectives to be met, the range of possible solutions and the approaches to be avoided.

### *Fire Safety: Means of Escape*

In most houses the only escape route considered will be to the ground floor; the option in institutions of moving people to another area on the same level will not apply. The *Guide* deals with escape in terms of travel distance within rooms, from rooms to a stairway or exit and along a stairway to an exit. It emphasises that the amount of help needed by people living in the house and the staffing support available should be taken into account.

In a bedroom where there is only one means of escape (i.e. down the stairs), the *Guide* suggests that people dependent on staff help to escape should not have to travel more than 12 metres to get to an exit, escape or a stairway or area ('lobby') protected against fire and smoke; other people should not have to travel more than 15 metres. These distances are guidelines and not hard and fast limits. If there is an alternative route the equivalent distances are 18 and 30 metres. Additional guidance applies to areas of very high fire risk or to rooms accessed only via other rooms but these are not likely to present problems in ordinary housing.

Only one door is required from a room if less than 30 people occupy it, so long as the recommended total travel distances are not exceeded. Doorways should usually be 750 mm wide but if people use walking aids they should not normally be less than 900 mm. This might be one of the recommendations given close scrutiny since, if an individual did not really require doors this wide and

providing them would delay or jeopardise their re-housing, it might be better to make do with ordinary doorways.

Fire safety in transit from rooms to a stairway or exit is primarily concerned with whether there is more than one way out. If there is only one route (i.e. down the stairs, through the hall to the front door) the recommendations are that the walls must be fire-resisting and all doors opening onto the route (including cupboards but excluding those from toilets) should be fire-resisting. If there is more than one route the *Guide* recommends fire doors to separate the two routes, with no more than 18 metres of uninterrupted hallway if people need staff assistance (30 metres if they do not).

The *Guide* recommends two stairways. flowever, it does say that one stairway may be acceptable if the following conditions are met:

1. the area of any upper floor does not exceed 150 square metres
2. there are no more than two floors above the ground floor
3. people who need staff help to escape do not live above first floor level (the *Guide* also recommends that people unable to walk should have their bedrooms on the ground floor)
4. the stairway exits directly to a door to the outside or by a fire-protected route to such a door (e.g. a hallway with fire-resisting doors onto it)
5. access to the stairway from any room is via two sets of fire-resisting doors.

In addition, the *Guide* recommends that stairways be enclosed, and that where enclosure obstructs alternative escape routes these should be re-created by cutting interconnecting doors between rooms.

Thus, these recommendations do permit use of ordinary housing without adding extra stairways (such as an external escape). The major problems are the



recommendations to encase the stairway and to have two sets of fire doors between bedrooms and the stairway.

Stairway enclosure is usually unattractive and intrusive in a house and may seriously hinder the ability of people who live there to participate fully in household activities. However, the *Guide* recognises this problem and suggests that it may be necessary to find "a specialised solution where the siting and location of smoke detectors may be a critical aspect and the availability of staff an iniportant factor". So it is open to the project organisers and the fire safety adviser to develop a package of added smoke detectors and taking full account of staff availability to retain an open stairway.

The idea of double fire doors is similarly unacceptable in most cases. The appropriate strategy here is to negotiate for a waiver, in which the local Fire Authority agrees to the use of single doors up-rated to one-hour fire-resistance instead of two doors of half-hour resistance. Again the level of staff support and the model of care are important factors to stress in this negotiation.

The sort of solution which is likely to be acceptable then, is to use a two-storey house with downstairs accommodation for residents unable to walk, to turn the hall and landing into a 'protected lobby' by making all the doors opening onto them one- hour fire-resistant and to provide an additional smoke detector in the stairway. Recently, very similar solutions have been proposed for small group homes in a Health Technical Memorandum *(Guide to fire precautions in NHS housing in the community for mentally handicapped (or mentally ill) people).* This is not intended to apply to staffed housing, but it could be argued that although the level of disability of people in staffed housing is greater the effect of higher staffing levels (and often a more carefully worked out household routine) is to remove any difference in ability to evacuate the building in the event of fire. The fire safety implications of furnishing the home are dealt with later in this chapter.

Building regulations for property in Group 2 also deal with environmental health issues. In the health service, there may be an environmental health adviser who needs to be involved in a similar way to the fire safety adviser. As before, the local authority adviser should be brought into the project at an early stage.

In terms of assessing property to decide on a suitable room layout the environmental health regulations have an impact on siting washing machines. Although many private houses have washing machines in the kitchen, environmental health advisers usually have a strongly-held view that, if any residents are incontinent, arrangements must be made for soiled linen or clothing to be laundered elsewhere. Effectively this means creating a utility area - not usually a problem in itself. The problem arises with the adviser's view that soiled laundry should not even be carried through the kitchen. This can often mean needing to create a small corridor out of valuable kitchen space.

Under these circumstances the most fruitful area for compromise seems likely to be to plan for a separate utility room or area, but to argue against creating a separate access on the grounds that, even if they are incontinent on arrival, the people who live in the house or flat will become functionally continent quickly, either because staff will use aids and assistance effectively or because they will teach people the necessary skills.

**Equipment, Furnishings and Decor**

Furnishing a home may seem a simple, even trivial, activity which it would be hard to get wrong. Starting from scratch, and using the supplies department of a service agency to purchase equipment, does however introduce much scope for inappropriate choices which ruin the care taken in housing selection. The issues are the same whether preparing the house or flat in advance of people coming to live there or enabling the future



residents to buy their own furnishings from local retailers. Judgments have to be made about quality, ease of use, durability, safety, attractiveness and fashion or personal taste which are common to everyone setting up home.

Mistakes in furnishing staffed housing often arise by the routine application of institutional practices (such as ordering baking trays too large for the oven or buying thin unlined curtains with no headings) and the misplaced inventiveness of people trying to design away what they imagine are the problems mentally handicapped people face. Thus, for example, it is common to find excessive safety precautions emphasising the lack of mature judgment of the occupants (e.g. tepid water from the hot taps and in the radiators, display of bathing regulations, guards on domestic equipment designed to prevent people using them or locks on internal doors designed to exclude resident access). A second risk is choosing excessively robust equipment and furnishings emphasising the lack of responsibility, care and competence of the occupants (e.g. melamine crockery, metal tea pots and serving dishes, metal furniture, unbreakable glass in the windows, vinyl rather than carpet floor coverings) or the special design of furnishings to accommodate disruptive behaviour (e.g. curtains fitted with a length of velcro fastening just below the curtain track, plastic armchairs or putting the television behind a screen mounted high up on the wall). The grouping of people together can also lead to inappropriate choices, as when a minibus is purchased instead of a car.

Internal decoration which would usually be found in a child's room is also common (e.g. wallpaper which has designs based on animal motifs or cartoon, television or book characters, the use of primary colours rather than more subtle, subdued tones), as is the selection of equipment and materials which, although functional, are designed to appeal to less mature tastes (e.g. clocks with faces decorated with pictures, posters rather than framed paintings or prints, and crockery with juvenile decoration).

In order to avoid these kinds of error, it is important to scrutinise every decision made, especially by supplies staff in the service agency. The general lesson to apply is that using vague descriptions like 'domestic' and 'homely[9]' is an insufficient guide to staff used to providing for institutions and that no issue is too small or obvious for someone to make a mistake.

All sorts of equipment (much crockery, cutlery, linen and all small personal effects such as table lamps, pictures, plant pot holders) can be purchased by the people served when they arrive, with help from staff. It may also be possible to use equipment on loan from the service agency for several weeks until people have had a chance to replace it with items of their own choosing.

Furniture and fittings will often have to be supplied by the agency. Here the problem is of restricted choice because of the agency's supply arrangements and sometimes because of fire safety advice (see below). However, it is possible, although more work for the supplies department, to purchase from suppliers it does not use to equip its institutions. Even where this is not permitted, supplies departments usually have a wider range of choice than is sometimes apparent: in the health service, for example, furniture catalogues for patient accommodation are full of formica, steel and vinyl, but the catalogues used to furnish doctors' accommodation contain polished wood and fabric upholstery.

Incontinence is most often cited as a reason for having vinyl flooring instead of carpet and vinyl-covered or even plastic easy chairs. Institutions are littered with attempts to provide 'domestic' furnishings which have been destroyed by incontinence. Given the wide range of aids and the extensive knowledge-base about teaching continence skills to people with mental handicaps, well-organised and well-trained staff can quickly help people achieve functional continence. However, thought does have to be given to what to do until this goal is achieved and how to cope with accidents or with problem behaviour.

For carpeting two solutions are to use good-quality wool-based carpet, either laid over an impervious sheet on top of the foam underlay, so that the carpet itself can be effectively cleaned and the underlay never absorbs liquids, or purchased with an impervious backing instead of a foam backing.

For soft furnishings the alternative to vinyl covers is to have the cushions and base covered in impervious material and then to have loose covers fitted, so that these can be removed and laundered separately. It is important to choose a closely-woven material with the strength to withstand sliding over the impervious layer. Extra sets of covers need to be purchased at the outset to replace those sent away for cleaning.

In terms of the overall interior decoration of a house or flat, the main issue is that it is difficult for the service agency to achieve enough variety in the choice of furniture and wall- and floor-finishes. The tendency is for all the bedroom furniture to be of one type, all the carpet to be one or two colours and so on. This uniformity and coordination is a subtle but powerful difference from people's own homes, where redecoration proceeds in steps and different styles are chosen for different rooms. Early redecoration and the purchase of individual furniture may help but it is sensible to seek the best possible solution at the outset.

### *Kitchen and Utility Equipmerrt*

The advice of the environmental health adviser may have the biggest impact on the design of the kitchen and it is important to have discussions at an early stage. As with other issues, not all advice needs to be followed; the task is to negotiate in a situation where there are very few real rules but plenty of opinions and a considerable mythology of what is necessary or prohibited.

The first issue an environmental health adviser may raise is the basic choice between a fitted kitchen and one in which movable steel shelving is used, so that every area of the room can be cleaned. Since only the former is likely to be seen as an attractive option by ordinary householders it is important to avoid the latter, paying attention to sealing the gaps behind units to avoid creating inaccessible areas where dirt might build up.

Among those things about which the environmental health officer may be more insistent is the provision of three separate sinks - a double sink and drainer for vegetable preparation and washing up, and a small wash-hand-basin. This is a good example of institutional practice unthinkingly carried over - people will follow the ordinary practice of washing their hands in the ordinary kitchen sink as they do in their own home.

A similar issue is the belief that mentally handicapped people are unclean and the crockery and cutlery they use should be sterilised, either by the provision of a scalding sink (i.e. a heating element fitted within the sink basin capable of boiling the water contained in it) or a dishwasher. The facts of the matter are that problems of the spread of disease among people in institutions have been due to the facilities and practices permitted by the service; disability has nothing to do with it. Faced with the need to compromise, most people have little difficulty in deciding they should opt for the dishwasher.

Other sources of concern deriving from institutional practice may be the separation of cooked and uncooked meats in separate compartments of the refrigerator (domestic refrigerators do not have separate compartments and separate shelves have to do) and the preference for a solid, free-standing floor-mounted deep-fat fryer instead of deep-frying on top of the cooker (a domestic worktop deep-fat fryer is the obvious compromise).

The one other issue relevant to kitchen design is arranging access for a resident who is physically handicapped, by providing a lower workshop area which a person in a wheelchair can sit at, and by using a built-in hob at an appropriate level. Where a house or flat is being designed for one or two people who both use wheelchairs then obviously the complete kitchen can be designed to be accessible.



Finally, there may be a requirement to have a specially-secure cupboard for medicines to satisfy the requirements of the Dangerous Drugs Act. The medicine cupboard should in any case be lockable, but if a special cupboard is required the main risk is that it will be much too large. Small versions are, however, available if people remember to order them.

### *Fire Safety*

The most visible impact on an ordinary home is the provision of fire doors, extinguishers, secondary lighting and automatic fire detection. If the property has been classified as Group 2 in the Building Regulations then this provision is likely to be inescapable. Inclusion of more sophisticated detection and up-rated doors may also have been conceded in order to secure a particular property or other desirable features like an open stairway or no need for a fire escape.

The Home Office *Draft guide to fire precautions in existing residential care premises* also recommends that floors between storeys should be capable of resisting fire for at least an hour, or where this is not possible for half an hour augmented by automatic fire detection. The commonest method of achieving this is to line ceilings with plasterboard, which may not be too obtrusive when complete.

Fire doors themselves are often heavy, difficult for frail people to open and the self-closing devices can introduce a claustrophobic feeling to the home. The development of a lightweight door with a self-contained closing device activated in the event of fire is probably the single most urgently needed technical advance that could be made in this area. In the meantime two practical steps are to avoid uprating existing panel doors by pinning fire-resisting material to them, since this makes

them too heavy, and investigating whether it is feasible to fit doors held open by an electromagnet on a specially installed circuit - although this entails extensive rewiring.

The *Guide* also recommends a fire alarm linked with break-glass call points, and where there is only a single stairway it recommends automatic fire detection (smoke and heat detectors). Self-contained detectors such as those available to the private home-owner are described as 'not acceptable at present'. If it is necessary to install automatic fire detection it is worth exploiting to the full the opportunity to dispense with some of the structural suggestions described earlier in this chapter. Although costly to install, they are relatively unobtrusive when compared with lobbies and fire doors. The further development of self-contained detectors may make this decision easier to accept.

The alarm itself needs to be heard throughout the building and to be loud enough to wake people who are asleep. It is most unlikely that more than one bell would be needed in a single property. Unlike extinguishers and call points, bells do not have to be painted red (they sound the same when painted to blend in with the walls).

An automatic alarm system has to have a control box sited somewhere. In a house or flat this box can be small and sited unobtrusively (in the cupboard under the stairs, for example). The traditional practice of siting the control panel as obtrusively as possible in the entrance hall is derived from large institutions where the panel indicates in which 'zone' the fire has occurred and needs to be immediately visible to the Fire Brigade on arrival. Houses and flats will consist of only one 'zone' and the control panel need not therefore be immediately visible.

A similar issue arises with fire extinguishers. The *Guide* recommends one 9 litre or two 4.5 litre extinguishers for every 100 square metres of floor area on each level, with special equipment (such as a fire blanket) in the kitchen. It is assumed that extinguishers need to be in the most visible places, although this is in part based on the rationale which applies to public buildings like institutions that people do not know their way around or where extinguishers are kept. In a small home where



people live for a long time, served by staff who are also allocated permanently to work with these people, it should be possible to select sites for extinguishers that are readily to hand but not obtrusive.

In the same way, it is unreasonable to require the display of notices. Better to arrange to provide realistic training for staff and residents and to make clear to the fire safety adviser that this is being taken seriously than to put up with disfiguring the home.

The *Guide* also recommends providing emergency lighting. In small homes this has usually been taken to mean battery-powered lamps in hallways rather than complete secondary systems or standby generators.

A second source of constraint on furnishing an attractive home comes from fire safety guidance on furniture. Fabrics (on furniture, curtains and duvets or bedding) are recommended to be treated with a durable fire-retardant which need not influence the look of the material. Some furniture, however, may need to be finished with a surface that has good properties of resisting the spread of flame. Typically this applies to bedroom furniture where a laminate finish is preferred to varnished or painted wood; beds with steel frames and a sheet steel panel below the mattress are also sometimes argued for. Whether the person whose room it is smokes cigarettes or not seems, sadly, to be ignored at the moment.

## **The** Standard **of Workmanship**

If the purchase and conversion of a house or flat is being carried out by a service agency, it is common for the technical staff who specify the design work, building alterations, decor and equipping of the house to operate at a fairly remote level. They may also be more heavily involved in schemes which consume much greater sums of money and are technically more complex. But although housing schemes for mentally handicapped people involve comparatively little expenditure, the price paid for the work done is often higher than a private person would pay. It should therefore be possible to expect a reasonable

standard of finish and durability.

This too is likely to take constant checking. The standard of workmanship may be influenced by the contractors' expectations of what will be accepted by service agencies and work may be carried out in a way which no private householder would permit (such as the repair of incorrectly installed electric wiring in a ceiling space by laying trunking over the ceiling surface in plain view, or tacking bright orange cable over the décor to fire alarms). Similarly it is important to choose furniture which is sturdy enough to be used by the number of people living in the home. Flimsy hinges and catches (especially on the kind of laminate furniture approved by fire safety advisers) can be a particular problem. The lining of ordinary doors with fire retardant material makes them extremely heavy, so that they are likely to pull away from the door frame.

If the initial standard of workmanship is not good, then the need for repair and renewal will become apparent sooner and the cost may be blamed on the mentally handicapped people living in the house rather than on the contractors.

**Further Reading**

*Draft guide to fire precautions in existing residential care premises.* (1983) London: Home Office.

Goldsmith S (1977) *Designing for the disabled.* London: Royal Institute of British Architects.

*Guide to fire precautions in NHS housing in the community for mentally handicapped (or mentally ill) people.* (1985) London: Department of Health and Social Security Health Technical Memorandum 88.

Turnbull H R, Ellis J W, Boggs E M, Brooks P O and Biklen D P (1981) *The least restrictive alternative: principles and practices.* Washington: American Association on Mental Deficiency.

# 5. Staffing

Staffing issues are at the core of housing services for people with severe and profound mental handicaps, because staff numbers and the quality of staff performance determine the help service users receive, and because staffing is the major component of revenue costs. The task facing the group developing the new service is to reconcile the needs of the people being served with the expectations of the funding agency - expectations which have been shaped by years and years of very low staffing levels in institutions.

Although people developing new services can expect a struggle to get the staffing support needed, it is vitally important to achieve this goal. Developing radical, innovative services in agencies that have been committed to institutions, at a time when those agencies are less willing to spend their scarce resources on the most deprived groups, is a risky business; holding out for the right staff for the job is probably the most important single decision made in the setting-up of the service. It is easy, and often fatal to the project, to accept people as staff who you know cannot really do the job.

The content of this chapter is divided into three areas. First, there is some discussion of how many staff people need and the staffing costs of different types of service. Following this is a section devoted to the roles and responsibilities of staff, including job descriptions, the personal skills and abilities needed by staff and the extent to which particular professional qualifications and experience are important. Finally, the third part of the chapter deals with the process of appointment - making sure that the advertisement and interview are consistent with finding the right people. This section concludes with a section on personnel policies, taking a broader perspective about the development and maintenance of a skilled and committed workforce in this kind of service.

## Staff Numbers

*Estimating People's Needs*

There are no standardised methods of calculating staff requirements based on a clear specification of the quality of life provided for the people served, not least because it is only now that a clear idea is being obtained of the wide range and complexity of staff performance required to address seriously the needs of people with severe or profound mental handicaps. So there are no 'golden rules'.

What is often used as a substitute are formulae calculated locally, which have sometimes been set as manpower targets. These formulae usually consist of two parts. First, there is a set of rules about hours of work, sickness, holidays and handover periods between shifts, which convert the number of staff actually available to the people served into the number of posts to be filled. Then there is a set of assumptions about staff ratios needed by people with different levels of disability. These assumptions are rarely based on anything more than committee decisions and may be very old.

Example 5.1 shows the formula used for deriving staff establishments in community-based residential services provided by Wessex Regional Health Authority. The Wessex method shows that, for every member of staff actually present during the working day (7am to 8pm), it is necessary to appoint 2.9 whole-time-equivalent (wte) posts, and for waking night duty 2.6 wte posts. Obviously these figures change if the working day is extended. However, the most interesting part of this example is the beginning assumption that there should be one staff on duty for every two people who have serious problem behaviour and one for every five others. This assumption was agreed at the beginning of the 1970s (and has not been reviewed since) and reflected a compromise between what people thought might really be needed to offer the people served a good quality service and what they thought was feasible in terms of costs.

This approach is really only useful at the project



*Example 5.1*

**Wessex formula for calculating staff establishment for a house for six people**

| People served | Number expected | Ratio | No.staff at any time |
|---|---|---|---|
| With 'severe behaviour disorder' | 2 | 1:2 | 1.0 |
| Other 'health service dependency' | 4 | 1:5 | 0.8 |
| Total | 6 | | 1.8 |

Day staff establishment: 1.8 x 2.9 = 5.2 whole-time-equivalent staff

Night staff establishment: 1 x 2.6 = 2.6 whole-time-equivalent staff

The derivation of the ratio of 2.9 staff for each person on duty at any time of the day assumes a working day of 13 hours (91 hours per week), an allowance of 8 weeks out of 52 off work due to holidays or sickness (i.e. at work 84.6% of the time) and a working week of 37.5 hours (actually at work for 31.7 hours on average). 2.9 staff working 31.7 hours are therefore required to deliver 91 hours staff time.

*The categories of people served by health service residential care in Wessex are based on assessments using the Wessex SPI/SSL Scale. Note that in this example there will be times of day when only one staff will be on duty.*

definition stage, when a rough idea of staffing levels is needed, often in the context of comparison with existing services. Once the first houses or flats are being planned around the needs of particular individuals, it is important to shift the basis for discussion away from these rather crude and arbitrary methods towards discussion of individual needs. So long as discussion about staff numbers remains at a general level it will be easy for decisions to be reached on the basis of comparison with poor-quality services or prejudice against people with mental handicaps. If the case for staff numbers is thought out in relation to individual needs and argued in terms of what kind of life individuals will have, it will be harder to accept bad compromises.

This individualised case need not be woolly and imprecise. The staff numbers required during the day can be estimated after considering four issues:

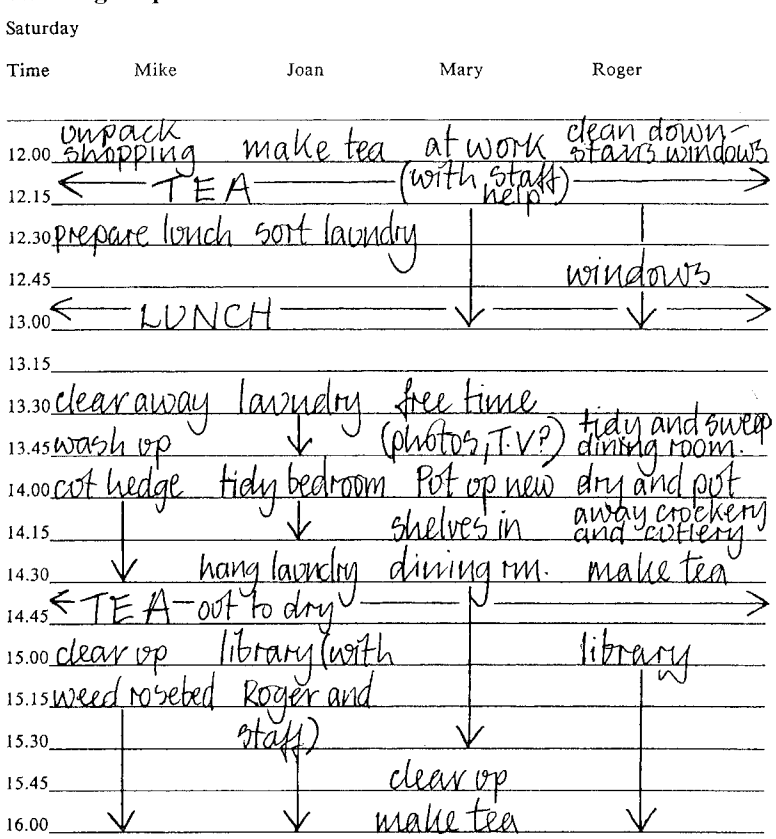
1. What kind of lifestyle the service aims to provide throughout the waking day
2. How much help the people living there need, both in terms of how often they need a member of staff and for how long
3. How well trained and organised staff are to help people operate at the limit of their independence
4. How much help staff can be expected to provide to the people they serve.

A useful way of addressing the first issue is to chart the sequence of activities and opportunities available to each person living in the house or flat at 15 minute intervals throughout a day (Example 5.2). For events which do not happen every day (like the use of amenities in the local area), a weekly chart can be drawn up to show how many different kinds of journey outside the home each person will take.



*Example 5.2*

**Part of a chart of daily activities used to estimate staffing requirements**




*Planners usually find it extremely difficult to construct this kind of statement of what life might be like for the people they are going to serve. The difficulty of filling the day with the categories of activity first thought of shows (i) that a rich and varied day has many more activities or opportunities in it than might at first be assumed, and (ii) activities often change rapidly, requiring staff to pay attention to scheduling sequences of opportunities.*

This provides a basic framework for the second issue to discuss how often people will need help from staff and for how long (whether someone is going to be left alone for more than a few minutes, for example). This must be thought through in terms of the individuals concerned, but as an illustration Felce *et al* (in press) found that people living in the two staffed houses they studied received instruction, on average, from between 36 to 96 times an hour (compared with just over once to just under eight times an hour in the institutional settings they studied). Different individuals living in the houses received instruction from staff from 6% to 41% of the period studied.

The last two items in this model deal with issues such as how many people can one member of staff help at a time; how well are they able to break activities down so that everyone can join in (how 'efficient' are they at helping people); and how much of their time they will actually spend interacting with the people they serve. These two issues interact, so that there is evidence that first, staff in poor quality settings only contact the people they serve for a small proportion of the time; second, simply increasing staff ratios produces diminishing returns and third, the absolute level of contact is improved by closer guidance to staff.

Taking these four factors together gives an indication of how many different staff are likely to be needed at different times in the day from which a proposed staff establishment can be worked out. This does however represent a considerable expenditure of time and energy and it may be sufficient for the purpose to produce, for one or two of the people served, an illustrative account of how they will spend their time and then to construct the claim for staffing on this basis.

A particular problem in estimating the need for staff is having enough help available at night. Traditionally, many social services settings have either had residential staff or day staff on 'sleeping-in' duties, while hospitals have waking night staff. If some of the people served have a history of wandering at night, or need regular attention



because of physical ill-health, or have lived in settings where for years they have gone to bed in the early evening and risen before dawn, then it is likely that there will be enough interruption and work to make sleeping-in unrealistic. Under these conditions it is sensible to have the option of deploying staff at night if needed: it is quite unrealistic to expect someone to work a full day after having been up most of the night.

However, this does not mean that waking night staff have to be the only option for ever. As people adjust to the ordinary rhythms of life and to the reduction of unnecessary medication, it will be possible to combine waking staff, on-call staff and 'sleeping-in' to provide a safe service which is not wasteful of resources. It is essential to preserve this amount of flexibility in setting the staff establishment and in defining staff roles.

Managers unused to anything other than traditional settings may be concerned about having only one staff on duty at night, in case the member of staff is lonely, afraid and eventually becomes disenchanted with the job without someone with whom they can talk. Sometimes the fire safety adviser argues that two staff are the minimum safe number (one to begin evacuation and one to call the brigade). Clear specification of jobs to do (especially writing up records) and telephone contact between staff help combat loneliness and boredom, while the ordinary security measures taken by other householders in the area at night help reassure staff. The idea that two staff are needed in the event of fire reflects the situation in hospital wards where there are many patients and only a few staff. Four or five people in a house among neighbours, with an adequate alarm and within four minutes drive of the fire station should be adequately served by one member of staff if there is clear guidance to the staff on what they should do in the event of fire.

*Staffing Costs*

Since staffing contributes the major part of revenue costs, decisions about staff numbers are often likely to be influenced by beliefs about the comparative costs of one sort of service against another. When entering this debate it is as well to be armed with some critical responses to the claims usually made.

The first issue is that it is widely believed that services which provide for people in small groups dispersed throughout the community will be more expensive than large centralised services because of 'economies of scale'. That is, the larger the setting the more money can be saved by bulk purchase of goods and services, by reducing travelling time and by reducing the number of staff needed to work with the people served.

Although often held to be a self-evident truth, there are a number of serious objections to a simple expectation of economies of scale. First, this kind of work with people is much less amenable to reducing staff numbers than other kinds of work. Since the service offered is individual help, encouragement and assistance, lower staffing levels may not be possible in larger services without accepting a fall in service quality. Dispersal will probably incur extra costs where general supervision is all that is needed - at night, for example, or in the balance of senior and basic grade care staff; but centralisation is not likely to mean that a high standard of care can be offered by many fewer people.

There is a similar problem with bulk purchasing. Since the product of the service is the kind of lifestyle experienced by the people served, a high-quality service will want to use all the opportunities for shopping and using community services as experiences for client care, whether they are grouped together or not. If block treatment is not wanted there may be little scope for savings due to bulk purchase and handling.

With travel costs, the problem with the 'economies of scale' assumption is that specialist services are needed by mentally handicapped people living with their families as



well as those in supported housing. In an effective service, specialists will be travelling through the communities where people live in any case. For many of these services, assessment in the real home or day setting is required so a central clinic model may in any case be inappropriate.

The last point about 'economies of scale' is that different services of the same type and scale may actually have quite different costs and any effect due to scale may be rather less than this existing cost variation. This variation will be due in part to genuine cost differences reflecting different practices in the settings, different client characteristics and so on, and partly due to idiosyncratic recording and charging of costs. Examples of this are described in two studies comparing the cost of 25 place units with large hospitals, and the costs of these with staffed housing, referred to at the end of this chapter.

An increasingly important example of this kind of cost variation is due to the occupancy of places in residential care. Typically, the cost of running a particular kind of setting is expressed as the average cost per resident day, in which the expenditure is divided by the average number of residents. Thus, settings which have places vacant (but which are still paying for staff, heating etc.) show as having higher costs than those with higher occupancy. Housing services may show lower occupancy than larger facilities because they offer a personalised service, where a place may be kept ready for someone who spends a lot of time living with relatives instead of being reallocated to a stranger. Similarly, if they spend time away from the home (with relatives or on holiday, for example) it may show in official returns as a vacant place. This is a fundamental problem in calculating the costs of residential services. The unit of service may not be a person sleeping in a bed overnight, and to use this as the basis for costing may obscure important aspects of the quality of the service.

This raises the second issue, which is the difficulty of comparing like with like when comparing residential care

costs. Any such comparison needs to take careful account of a number of sources of error due to differences in what is being compared.

The most obvious source of such error is failure to take account of the characteristics of the people served. The smaller the unit of analysis, the more the costs will be influenced by individual characteristics as reflected in staffing ratios and running costs. Thus, for example, in comparing houses with hospitals the hospital costs will need to be adjusted to take account of the different staff ratios in different wards. A house staffed to serve people with severe or profound handicaps needs to be compared with a ward serving people with similar levels of dependency. This is also true for domestic staff costs.

Secondly it is important to include all the services involved. For example, housing services are usually staffed by people who help the people they serve do all the housework and cooking as well as physical, social and psychological care. It is therefore important to include care staff, domestic and catering staff in any comparison of staff levels with larger facilities. If community-based services include staff who act as employment facilitators or provide some other day care service this too needs to be taken into account, since about 25% of hospital residents have no daytime occupation off the ward. Similarly, if the staffing structure combines family support and residential care staff in patch teams it needs to be carefully matched to the comparison service.

The third question worth considering is whether the comparison service is staffed to its target level. Large hospitals often experience recruitment problems (whether because they cannot find enough applicants or because they are easy targets for cuts during the year) so that their actual staffing level, and hence cost, may be lower than it would be if all posts were filled.

These are all issues to do with the measurement of costs. The final question to bear in mind is whether comparisons take account of the outcomes experienced by the people served. Poor quality services will no doubt usually cost less than high-quality services. In comparing



a new community-based service with a traditional hostel- or hospital-based model of care, some evidence of the kind of life the service produces should be an integral part of the debate.

## Roles and Responsibilities

### *Defining the Job to be done*

The first obligation of an organisation is that it should be able to say to the people it employs exactly what it wants them to do. If this is unclear, it is hardly surprising that people fall back on traditional patterns of work or focus on only those parts of the job which have been clearly specified (like administration).

The central feature of the job expected of people working in staffed housing services is that they support the people they serve in the full range of activities and tasks involved in a rich and varied lifestyle. This means that they must have the skills to fulfil several roles, often at the same time. They have to be friend, teacher, cook, cleaner, nurse and repairer. There is no realistic alternative to this approach, both because the numbers of staff serving a household are so small that separate cooks or cleaners cannot be employed for all the time they are needed, and much more importantly because all these different household activities must be available to the people living there. When there are different groups of staff it seems impossible to avoid a drift to excluding people from what are seen as the staff's jobs.

If the decision has been made to integrate care staff serving families and those supporting people in housing as a local 'patch' team, or if the staff will also help people find alternatives to traditional day care (by acting as 'foster-workers' in employment, for example), then this also needs to be clearly spelled out.

As well as defining the range of tasks and responsibilities, it is also important to state the parameters

within which people will work. In a service which provides staffed housing without discriminating against people because of the severity or their handicap or problem behaviour, staff need to know that if they take the job they do not have the option of excluding people whose needs they have difficulty meeting. Since this is in direct contrast to most services they will have experienced it needs to be clearly stated. Similarly, they should understand that the aim of the service requires that staff assist the people they serve carry out household activities, even for the people with most difficult handicaps, rather than that the staff make a token effort but essentially exclude the people served while they do the job. If the design of the service requires staff to change their working hours, either because of varying demands for cover at night or because of changing circumstances or sickness, then the job description should say so.

As well as setting limits for the care staff, there are issues to do with limiting the scope for reverting to traditional methods by managers. The team leader in a staffed housing service needs a clear statement that they are responsible for the operation of the service throughout the full 24 hours, including managing the budget and the staff (Example 5.3a). Some thought needs to be given to whether staff are employed to work with a particular group of people because, if they are not, managers may redeploy staff between settings as an easy response to sickness or absence. Although this may be a reasonable solution in rare circumstances it is very easy to fall into the traditional hospital system of moving staff around all the time; this has clear advantages for the managers, at least in the short term (it avoids having to deal with the root cause of high sickness/absence) but has serious disadvantages for staff and the people they serve (committed staff who turn in to work on that shift get punished by being sent to places people find less motivating; the people they serve get fewer staff; and some get staff they do not know well, if at all).

Example 5.3b illustrates the level of detail which is likely to be needed in spelling out the job description of



*Example 5.3a*

**Job description for a team leader in a staffed housing service: basic statement of responsibilities**

The team leader is responsible for all aspects of the day-to-day running of a staffed house for 5 people with severe or profound mental handicaps. They will lead a team of a deputy, five day staff and four half-time night staff. The staff team is responsible for helping the people they serve in all aspects of their home lives - personal care, housework, meal preparation, shopping, leisure, gardening and social and community activities.

The operational policy for the service is based on the principle of normalisation and emphasises (i) the participation of the individual in social and community life, (ii) enabling the people served to undertake all the activities of daily living by providing sufficient help, (iii) an orientation to each person as an individual who will continue to develop in confidence, ability and experience, no matter how severe their disability and (iv) keeping high standards of respect, courtesy and an attractive environment. The team leader and their staff will have considerable scope for contributing to the development and enhancement of this policy but will undertake to work within the policy as agreed with the project management team.

The team leader is accountable to the project director.

*Example 5.3b*

**Example of a section of a job description for a team leader itemising tasks relating to enabling individual participation in meangingful activity**

1. Organising the day to promote the active participation in activity of all the people served, including those with profound handicap or added problems. The aim is for everyone to have the opportunity to join in a useful and interesting activity at all times, so that doing nothing is a real choice rather than enforced by lack of opportunity or help.
2. Showing staff how to encourage participation effectively (both in terms of providing graded levels of help and of providing encouragement and motivation) while at the same time not fostering undue dependence or encouraging problem behaviour.
3. Determining the way the house should be organised and the standards to be achieved, and allocating staff to duties.
4. Arranging activities outside the home in which individuals who live there can participate, especially those activities and situations where the individual's disability is less obvious or relevant.
5. Ensuring that the activities, the materials and equipment used and the rhythm of the day reflect the chronological age of the people served and are consistent with those experienced by other people.
6. Implementing a system of checking the extent of participation in activities to allow staff to review their work and to help safeguard the range and variety of opportunities made available to the people served.

*Other sections might spell out responsibilities in areas like planning the care of individual people (dealing with individual programme planning, individual programmes of teaching or treatment, attending to individual relationships etc), the supervision of staff and personnel functions (hiring and firing, supervision and counselling, training and management) and administration (budgets, standards, records).*



a senior member of the staff team. Example 5.4 is a much shorter statement designed for members of the care staff team.

One other issue in defining roles and responsibilities is striking the right balance between senior and basic grade care staff. When deciding on a particular staffing structure, there are three areas for which this balance has implications: supervision of staff, career development and decision-making. Senior staff have an important educational function working alongside other staff: if they share the contingencies of the care staff's job they are more likely to frame realistic expectations for staff performance; they can provide a good example on which staff can model their own work; and by demonstrating their own competence and confidence they increase their credibility with staff. It is of course also desirable for the people being served that they get a share of the most skilled staff time. This implies that each basic grade staff has some time each week working side by side with senior staff (which itself has implications for staff rotas and for delegation of office work).

Looking further at this educational role, there need to be enough deputy team-leader or senior care staff positions to enable people to progress within the organisation - a point discussed further below.

Given the need for a range of senior staff positions both to provide adequate supervision and to allow for career development, it is worth avoiding creating jobs of exactly equal status (i.e. have a team leader, deputy and senior care assistant rather than a team leader and two deputies). This avoids possible conflicts in approach being carried through into practice where the team leader is unable or unwilling to resolve the issue. The worst examples of this find deputies leading opposing shifts in contradictory approaches, while the senior person hides behind their desk doing administration.

*Example 5.4*

**Job description for basic-grade staff**

1. Staff are responsible for the care of people living in the home, all of whom have severe or profound learning difficulties and some of whom have extra problems of physical handicap or challenging behaviour. The people served by this project have families living locally.

2. The project is designed to provide a home for people no matter how severe their learning difficulty or other problems, for so long as it is in their best interests.

3. Day staff will work shifts covering the period from 7 am to 10 pm; night staff will cover 10 pm to 7 am. Day staff will attend a weekly staff meeting unless on leave. Night staff will attend according to a rota. Times of work may be altered to fit in with the needs and preferences of the people served, and day and night staff will occasionally work on the other duty.

4. The staff will share all the caring and housekeeping tasks - there will be no cooks or cleaners. Everyone will therefore share in

   4.1. Physical care - helping people get up, dress or undress, wash or bathe, use the toilet, eat at mealtimes, and so on

   4.2 Enabling individual participation - setting up everyday activities and experiences so that each person can join in, no matter how handicapped they may be

   4.3 Housekeeping - helping people undertake all the cooking, cleaning, shopping and other housekeeping activities necessary in running a home

   4.4 Teaching - carrying out special teaching sessions several times a day following written programmes

5. Every aspect of the home will be organised so that the people who live there can do as much as possible for themselves. The role of staff will therefore be to help, even if it takes longer, rather than to do things for or to people.

6. Guidance and direction on the best way to do the job will be available from the team leader and their deputy. All staff will work within the framework of the operational policy for the staffed housing project.



*The Skills and Qualities Needed*

Senior staff need commitment, skills and experience. They will have to find imaginative solutions to new situations in the face of demands to compromise on principles. Strength of commitment to these principles at the outset is therefore one of the qualities to search for in appointing new staff. But commitment alone will not be enough to overcome the problems; staff also need the skills of organising the residential environment and working with mentally handicapped people, and the confidence which comes from experience.

Apart from a commitment to serving severely and profoundly mentally handicapped people in the community, backed up to some extent by an appreciation of normalisation and the principles of applied behaviour analysis, senior staff also need a commitment to a participative, democratic style of leadership if they are to fulfil the role of teacher to their own staff. This does not mean that they should never have any idea of what to do - that they should only be capable of leading their staff from behind, expecting them to generate ideas and solutions. It means that senior staff need the ability to coach people away from negative, despairing, blaming perspectives on problems towards constructive interventions, providing the ideas to fuel this process if needed.

For senior staff, the roles of leader, administrator and presenter have to be added to those of the basic-grade care staff (friend, teacher, cook, cleaner, nurse and repairer). None of the skills involved in this complex job are the unique preserve of any one profession and the full complement extend beyond the areas currently included in basic training for nurses, teachers or social workers - not least because much practical training is necessarily carried out in institutional environments. It may help in the interview if the skills required to fulfil these roles have been spelled out beforehand, especially if some members of the interview panel may be inclined to accept

professional qualifications as evidence of suitability without any more detailed evidence.

The need for experience is partly to allow the interview panel to confirm that the applicant can actually do what they claim and partly to ensure that the person appointed will be confident in meeting new demands on them, either because they have direct experience of the situation or because they are used to routine problem-solving. At least three areas of experience are important: (1) work in a small community-based setting, where the staff were much more autonomous than in a larger facility and had to solve more problems themselves; (2) work with people who have severe or profound mental handicaps who need staff to help them participate in many ordinary activities; and (3) work with behavioural approaches (although it will be important to distinguish good experience from exposure to mechanistic 'behaviour modification' of the form practised in some places).

Finally, the selection of basic-grade care staff needs to take account of balancing strengths and weaknesses among different applicants. Because care staff wages are very low it is hard to appoint people who are sole wage-earners for their family; in practice this means that most applicants will be young women without children. The goal should be to achieve a mix of both sexes and different age groups (and local ethnic groups) in the service. This is important for three reasons. First it is necessary in order to provide appropriate role models for everyone served, so that (for example) older people can choose their clothes or accessories with help from staff of a similar age group. Second, a mixed group of staff allows the inclusion of staff who have special skills in household repair or in organising family life, so that the group can include all the competencies needed even if each of its members lacks some relevant skill. Third, a mixed group of staff is more likely to be seen as representative of the local community by members of that community; it will have more informal routes towards social integration and will be less at risk of being seen as deviant.



## Appointing the Right People

### *Advertising*

The purpose of the advertisement is to attract as many applicants as possible so that short-listing and selection can be based on the widest choice: *good people are scarce*. This means both placing the advertisement where it will reach the target audience and ensuring that it is worded to avoid discouraging applicants.

For senior care staff, the target audience will usually include people with proven experience and/or a qualification in residential social work, nursing or teaching. The advertisements therefore need to be placed in the professional journals of these three groups. Although obvious, it is surprisingly often the case that this is left to the personnel department of the agency, who follow past practice by advertising only in the journals of one profession, guaranteeing a much reduced field of applicants. Advertising more widely need not cost more if one journal is selected for each group rather than the common practice of advertising in several.

Similar care needs to be taken over the wording of the advertisement itself. People read advertisements very carefully, looking for every clue to the employer's wishes and intentions. As well as saying clearly what the new service is about, it is important to make sure that none of the other features of the advertisement (which section it is placed in, where applications are sent, how the salary scale is described) might suggest that some members of the target audience should not apply. This may well entail checking every detail just before the advertisement is placed. Examples of common problems are advertisements for senior staff from any background where the personnel department inserts "Salary will be abated for staff without nursing qualifications" or "New entrants start at the bottom of the scale".

For basic-grade staff drawn from the local community, where applicants are not expected to have special qualifications or experience, the advertisement needs to

say clearly that this is the case. It may also help to say that applications would be welcomed from men as well as women, and from mature as well as young people. Applicants should be invited to contact the senior member of care staff rather than anyone else for informal discussion (so that both parties size each other up at the beginning). In giving this information, and in any other aspect of the advertisement, it is important to avoid drawing attention to the addresses of staffed houses or flats to preserve the privacy of the people served.

All applicants should receive extra information with their application forms. Since housing services are relatively new and there is no single professional group with a monopoly of relevant skills, the information routinely asked for on official application forms will not be enough. Potential applicants may misunderstand what is involved (they may assume that because the service provides housing it excludes people who need lots of help, for example), they may not realise the commitment you are asking them to enter into, or they may just not say very much about their particular skills and expertise. The extra information should include the operational policy of the service (so that they can be asked at interview whether they are committed to working within it), the job description and guidelines to candidates which say plainly what is wanted in the job and encourages them to provide enough information on which to base short-listing. Example 5.5 illustrates the kind of advertisement which might be used, and guidelines to candidates are given in Example 5.6.

It may also be appropriate to ask candidates for senior staff posts to produce some evidence of their skills beyond that asked for in the guidelines to candidates. Senior staff need the conceptual, analytic and writing skills involved in finding imaginative responses to individual needs in a whole range of areas which, in the past, they have not usually been pressed to tackle. Some



*Example 5.5*

**Draft advertisement for staff team leader**

**Senior Support Worker**

To lead a team of 10 full and part time staff supporting four people in an ordinary house in _____. These people (three women and one man) have lived in hospital for some years and have severe learning difficulties. Their new home is not associated with a mental handicap hospital.

Applicants should be committed to a policy of caring for everyone, no matter how severe their learning difficulties, in ordinary housing in the community. They should have experience of residential care in the community and of working with people with severe learning difficulties. They will need to show both a clear understanding of and commitment to the 'ordinary life' model of services, and to demonstrate they have some of the skills to achieve this in action.

Appointment is open to applicants with any of a range of qualifications (eg in teaching, social work or nursing) or to unqualified applicants with good experience. Salary scale from £_____ to £_____.

Further information, application forms and job descriptions can be obtained from _____.
Informal enquiries can be made to _____.
Closing date _____.

*Example 5.6*

**Guidelines for applicants for a staff team leader post**

In trying to select the best people for the job we have found that the standard application form does not encourage applicants to provide the information we need. This brief summary has been prepared to help applicants get a clear idea of the main features of the job so they can spell out relevant experience in their applications.

This project is a house in a residential area and is not part of any hospital or hostel complex. The team leader will be expected to develop considerably autonomy and be prepared to take responsibility for making many of their own decisions. They will coordinate and manage the work of a team of staff (who will be responsible for all caring, housekeeping, activity and teaching). Applicants should therefore describe how they have provided leadership and management in these tasks before and how they would envisage using the opportunities of the new service (rahter than simply listing the positions they have held).

The people served by this staff team include several individuals with challenging behaviour and every person has severe or profound mental handicap. The emphasis will therefore be on helping people participate in household and community activities in spite of their problems and on providing as much help as is needed to maintain real participation and achieve greater independence. Applicants should therefore describe their own practical experience in helping people with severe and profound mental handicaps participate in these activities and in using individualised programmes of teaching or treatment. Accounts of actual methods used (leaving out the names of the people served) would be relevant to include with the application.

The successful candidate will be someone who has taken an interest in changing models of care for people with mental handicaps, who identifies strongly with the 'Ordinary Life' philosophy of services and is able to argue the case effectively with people who doubt its relevance. Applicants should therefore express something of their knowledge of recent developments in services for people with mental handicaps and their views about them.



candidates with relevant experience may not actually be able to observe or analyse behaviour accurately, or construct a teaching strategy that bears examination, or teach basic-grade staff well. It is good practice therefore to ask applicants to append an account of what they consider to be their best work in one of these areas and to come to interview ready to discuss it.

*Interview*

The task of the interviewers is to find out to what extent each candidate matches the skills and qualities needed and to test the experience claimed in the application. A formal interview should play only a part in the process of selection. It can be used to probe the depth of understanding the candidate has, but it is less effective at checking practical and interpersonal skills and it is not necessarily an easy format in which to involve the mentally handicapped people the staff will serve. Informal opportunities should be arranged for candidates to meet the interviewing panel and for each candidate to meet and spend some time with the people they will serve. Candidates for senior staff posts should also meet managers and other key staff.

Since many people can talk relatively convincingly about helping mentally handicapped people in community settings even though they cannot do it, part of the informal meeting with the people served should provide opportunities for the candidate to help carry out everyday activities so that they can demonstrate their practical skills. Clearly it will not be possible for the candidate to do very much, but joining in housework or a shopping trip will make it much easier to judge whether the candidate can interact helpfully and appropriately, whether they use opportunities to enhance the individual's competence and their image in the community and whether they can organise the situation to the best advantage. This practical experience can be coupled with discussion in the formal interview of the candidate's

knowledge about and approach towards working within the context of normalisation using behavioural methods.

The need to probe the candidate's ability to deliver means that someone on the interviewing panel has to be able to distinguish good from indifferent practice. The ability of existing care staff managers to do this cannot be taken for granted, so there may be a role for bringing in an outsider specifically to take care of this issue.

Special consideration needs to be given to involving the handicapped people concerned in the interview process. The issues involved in deciding how to do this are similar to those which arise in Individual Programme Planning (see Chapter 8). The informal meeting with each candidate provides one opportunity for people to express their preferences or for others to gauge their responses to each person. People living in the house or flat who can participate in a formal interview should be members of the interview panel; the chairman of the panel can help structure the discussion so that everyone can join in.

Other people the successful candidate will have to work with should also be represented in the interview process. These will include the people leading the development of the service and, for a replacement appointment, other staff (including basic-grade care staff for a senior appointment).

The final point about interviewing is that the panel often perceive the need to make an appointment as more important than finding the right person. The pressure to appoint comes from the desire to get a new service going or to avoid incurring extra costs of advertising and interviewing. The consequences of an ill-considered appointment, however, can be very serious. In Britain it will usually be very difficult to remove the individual from the post, because they will be able to show that they are not much worse than many staff in poorer-quality services, because employment law requires that the employer's demands be reasonable (why was the candidate appointed if they cannot do the job?) and because they will not be suitable for promotion. For the candidate, their need to demonstrate to themselves and others that



they are competent will lead them to try to conceal poor performance, hiding from the people served, their own staff and from managers, both figuratively - by spending time on tasks they know they can do well, like administration - and actually - by spending almost all their time in meetings and their office rather than with the people they serve and their staff. They will need to seek justification for failure by blaming others. The vulnerable people to blame are the people being served: thus staff will say that 'people are too handicapped' to participate in a full range of activities of daily living.

## Personnel Policies

### *Terms and Conditions of Service*

Without doubt the major issue in sorting out the terms and conditions of service of people working in services providing staffed housing is the difficulty of matching the needs and expectations of people appointed from different professional backgrounds with the rules imposed by the employing agency. Thus, for example, new entrants may be expected to start at the bottom of the scale even if they have extensive qualification and experience with another public service. The salary scales offered to people doing the same job may be widely different if they have different professional backgrounds, and the pension and benefit entitlements may also vary markedly.

Given the existence of (separate) national bargaining arrangements for staff of local authorities and the National Health Service there are two approaches to dealing with this problem. Either wait for a national solution, or find a way round the rules at local level so that staff feel they are being fairly treated. In taking the latter course, it is important to work closely with a helpful personnel specialist in the host organisation before the issues become crystallised. This maximises the

opportunity to set up the terms and conditions in the most flexible way before vested interests are required to vet the proposals in a public forum.

Another issue in the terms and conditions of service of staff relates to the mutual expectations of employer and employee. The job description is a statement by the agency of what it expects from the staff it employs. As staff are appointed it is worth considering augmenting the job description in two respects: clearer guidance to the member of staff on the kind of issues where they are expected to ask for help, and what help the member of staff can reasonably expect from the agency itself.

This statement should be written down, for the protection both of the member of staff and their manager. The sort of situations it might specify where a staff team leader was expected to refer to their manager could include: accident or injury to one of the people living or working in the house or flat, a major argument or dispute in the house or with a member of the public, the need for help to tackle a particular individual need effectively (whether in personal growth and development, health care or helping someone manage their behaviour) or where the team leader does not know what to do. Listing these items is insufficient: the aim should be to define as clearly as possible for each item the kinds of issue which would be serious enough that managers would expect to be informed.

The other side of this coin is just as important: what help can the member of staff expect from their managers? The team leader will have considerable autonomy to run the service; the other side of this coin is that they can easily become isolated and their managers can set them up to take the blame when problems arise. The project organisers of a staffed housing service need to have worked out clearly who the team leaders can go to for advice or practical help in the tier above them. Peer support has a part to play, but arrangements need to be made for managers to take some ownership of problems that arise, to think up appropriate courses of action and to help see them through.

The kinds of help the manager makes available might



include: time to discuss the issue face-to-face with the manager, practical help in which the manager takes on part of the job as their responsibility to sort out, extra staff time for meetings to talk about the problem or to tackle it directly (overtime, paying volunteers or taking on another person for a fixed period), intensive advice and consultation with a specialist adviser or professional, hands-on help from an adviser or professional, or time away from the day-to-day pressures of the job to work out an appropriate solution. Here too there needs to be an agreement about how much help will be available and under what conditions.

*Staff Development*

The first task facing a developing service is to attract good people to get the service off the ground. This may cost more in presenting attractive conditions of employment; it may require imaginative solutions to problems of grading and accepting unusual qualifications; and it may mean designing the service to be more innovative and therefore more appealing.

An emerging service is not, however, likely to find enough competent people without investing in training and promoting its own basic-grade staff once the service gets going. Partly this is a question of devoting enough resources to facilitate staff development. This needs to include several strategies. A systematic programme of in-service training is needed so that new staff acquire skills and experience with good supervision and teaching from senior staff and existing staff can take advantage of 'refresher' opportunities. Resources need to be obtained to second people for off-site training, either on professional training courses in social work, teaching or nursing or on specialised courses dealing with particular skills (such as behaviour analysis, community development or property management). Financing the staff replacement costs that keep service quality at a good level and so maintain the commitment of staff to participate in training is also an often overlooked but important component.

Another issue is for the service to overcome traditional

prejudices against internal applicants, especially those without formal qualifications. The failure of many services to cultivate local basic-grade care staff as potential candidates for senior posts seems to have its origin in two problems. The managers and personnel staff, themselves often professionally qualified in social work or nursing, are often much more likely to recruit staff from their own professional background even where the formal policy is more open to finding the right person irrespective of formal qualification. Under these conditions, the representation of staff with traditional qualifications increases gradually and basic-grade staff recognise this informal pattern of discrimination and become less likely to apply for promotion. In addition, internal candidates are likely to be at a disadvantage when the interviewers are unable to tell those who can do from those who can just talk. For the internal candidate, their faults are well known to the panel and they may compare unfavourably with candidates from elsewhere who present a plausible, polished appearance in the formal interview.

Finally, the service has to design routes by which the most able staff can continue to progress in their careers without leaving the organisation, so that, at least to some extent, the service offers planned career progression. Job-aids exist that are directly analogous to individual programme planning, in the form of staff appraisal and development reviews, which can help focus on relevant issues if used with creativity and imagination. The future for individuals may be in service management, with the opportunity to progress from managing a staff team to a group of teams and eventually to running staffed housing for different client groups in the same area. Or it may be in providing career opportunities for people as acknowledged exemplars of the front-line management task, with responsibilities for pushing the definition of service aims further forward (re-drafting the agency's policies) or staff training or offering individual consultation to other staff in their peer-group. In this way, the service not only attracts good people and makes them better at their job, but also it keeps them for long



enough to make the most use of their experience and commitment.

**Further Reading**

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# 6. Establishing the model of care

This chapter deals with moving people into the first accommodation in the staffed housing service. Underpinning this transition from plans to action is another process, that of turning the aspirations and ideals of the project into reality in the model of care. Establishing the model of care properly at the outset is crucial: opening a new service wipes the slate clean (in many respects, at least). Whatever their background, their history or the reputation they have accumulated over previous years, the move provides a fresh start for the people served and the staff who work with them. For the service as a whole, there will never be another opportunity for such thoroughgoing re-design.

Getting things right at the beginning also provides a secure base on which to develop the confidence and competence of staff. Once operational, people in the service will settle into particular ways of doing things and any change, no matter how desirable, will incur costs of readjustment. If important areas of household organisation are left unplanned people will have to invent their own solutions, which may not be the best for service quality (although, since they thought them up, people will be more likely to defend them). Instead of starting smoothly and well so that staff can use their own initiative to further develop the service, their early experience can be of muddle and failure and of feeling that no-one knows what they should be doing.

Paying particular attention to establishing the model of care also recognises the relative weakness of the variables traditionally manipulated by service planners. The belief that all that is really needed to improve mental handicap services is to plan new kinds of accommodation and to bring in new staff is simplistic; it ignores the extent to which poor quality care in traditional services is the direct product of ideas about who people with mental handicaps are, what they are worth and how they should



be treated. Although no doubt fed by the form services have taken, these ideas have a wider currency in the population and, in the absence of clear guidance on aims and methods, it is perfectly possible for staff with no background in traditional services to develop institutional practices. The buildings, their furnishings and the staff provide only opportunities, to be used or ignored. It is the task of the project organisers to show staff how these opportunities can be used to the full.

This chapter is again divided into three parts. In the first section the implementation of the operational policy is discussed, including the administrative arrangements for obtaining goods and services and policies like those for the safe handling of medicines. The second section deals with preparing the people to be served for the move, including preparation in the 'old' setting and reception in the new home. The chapter concludes with a discussion of the organisation and deployment of staff in the first months of operation and forms a bridge between this and the next chapter which deals with staff training.

## Implementing the Operational Policy

### *Handling Money*

The aim is to devise a system of managing money which most closely follows ordinary family budgeting arrangements, and is also consistent with good accounting practice for the protection of the people served and the staff who work with them.

Primarily this involves creating a shared 'house account' from which the pooled resources of the people living together can be used to pay their communal expenses. Each individual then has a personal account or accounts from which to meet their own needs (including saving, if appropriate). The shared account can be a separate account at a bank or it can be an account created within the budget of the staffed housing service.

Depending on the status of the people served it can be funded by contributions from individual residents (using social security) or directly from the service agency (where people are ineligible for social security because they are 'patients' or 'residents').

Where possible, a cheque account should be used to reduce the amount of cash which has to be handled. As in any family, payment can then be made in one of three ways: bills for utilities and services (telephone, gas and electricity, etc.) can either be paid by cheque or passed to the service agency for payment; some other bills (for weekly shopping trips or furnishings, for example) can be paid by cheque; and incidental expenses can be paid with cash.

Reducing the need to handle cash helps meet accounting requirements but it is not desirable to try to remove cash handling altogether. Attempts to require shopkeepers (especially those with small, local shops) to open accounts with the service agency are inconvenient and stigmatising, as is requiring receipts for every purchase. A combination of several shopping trips each day to make a few purchases in small shops and a weekly supermarket trip is likely to be essential to provide the people served with a wide enough range of experiences and opportunities. As in other areas of the service, a balance has to be struck between the needs of the organisation and those of the people it exists to serve. If staff are trusted to work with people who need help in almost every area of their daily lives then trusting them with money should not be too difficult for the service agency.

It is also important to avoid imposing unreasonable demands on good practice by staff by requiring that every item of expenditure is agreed by line managers. Not only does this make it easier to give up trying to provide new opportunities for the people served, it also sets the occasion for a punitive relationship with the line manager and it is likely to ensure that staff skills and confidence do not develop. Agreeing an outline budget with agency staff responsible for verifying expenditure makes it easier



to cope by establishing a target for expenses met in cash each week. There does, however, need to be some agreed level of flexibility to save and to transfer across budget headings without always needing approval.

### *Obtaining Goods and Services*

Shopping for food and other consumable items is a central focus of daily life which staff will need to exploit in working with the people they serve. No attempt to impose bulk purchasing arrangements via agency supplies should therefore be permitted; it is, in any case, not clear that such arrangements are really that much more economical, given the waste involved in using large containers - setting aside the problems of extra storage, delivery by truck in the street and the withdrawal of important life experiences from the people served.

Some kinds of aids (such as incontinence aids) would normally be supplied by a service agency to any individual in the community. In this case, collection from a local source of supply (eg a health centre) as a kind of shopping trip can be used as an alternative to delivery.

Supply of medicines may vary depending on agency requirements and the arrangements for primary medical care. Where possible, people should register with a family doctor and obtain prescribed medicines from a pharmacy in the community. Each type of medicine is then dispensed individually and there are no 'stock' prescription medicines to keep tally of.

Staffed housing provided by the health service, where the properties are in a sense just another kind of health care premises, may encounter difficulties in achieving this goal. A community pharmacist may have problems obtaining payment from the pricing authority if that authority holds that the cost of medicines should be met by the local health authority. This issue also arises with some other paramedical services such as dentistry and chiropody, where the assumption is that payment for these services has already been made through the hospital

service budget. The implication of this policy would be that people living in staffed housing in the community provided by the health service would have to obtain paramedical services from the hospital service (and in practice often from the under-resourced service provided by the nearest mental handicap hospital).

This position is not always held and can be expected to weaken as more services develop in the community. It seems that this objection is less likely to arise if the individual person needing medicines (or dental treatment or chiropody or any other similar service) is assisted to make their own arrangements with local practitioners in the community as a private citizen; the mechanism for detecting the irregularity is not very effective. Alternatively, the service agency (the local health authority) could try to negotiate at agency level a contract with the pricing authority to buy community services as those based on institutions were replaced.

Particular attention also needs to be paid to arrangements for repair of equipment. It seems likely that the quickest service, the best standard of workmanship and the keenest price will be obtained by empowering staff in the individual house or flat to make their own arrangements with local tradesmen. If some sort of agency contract is insisted upon, it is essential to write a clear agreement in the operational policy about speed of delivery of service and quality, and also to include some kind of waiver to avoid being obliged to wait, for example, three days for a qualified electrician to replace a fuse in a plug. Similar arrangements need to be made for the replacement of furniture and furnishings and the maintenance of the fabric of the property (including redecoration). The issues discussed in Chapters 2 and 3 apply to replacement and renewal as much as to new provision and Chapter 11 (Quality Assurance) also has a section on the monitoring of accommodation standards.

One sensible exception for an agency contract is the automatic fire detection system, where fitted. Here it makes sense to have an agency-wide contract with the installers since the expertise will not be readily available



locally. It is still important, though, to specify in the contract a definite commitment to respond within a few hours.

The last issue in providing goods and services is how the household is designated on bills and in the telephone directory. On bills, the use of the service agency name followed by the address is perhaps only likely to influence the postman's perception of the property; an easy alternative is to nominate one resident as the notional householder (perhaps different names for different bills). The telephone directory is a more public source of information. If the aim is to protect the privacy and anonymity of the people served, an appropriate solution is to pay to have each resident's name listed, with one person nominated to receive the bill. In this case it is also important to avoid listing under the agency name or indeed in the agency's own documentation.

### *Safety Procedures*

During the planning of the service various assumptions will have been made about several kinds of safety procedure. The design solution for each property will have been influenced by assumptions or undertakings about fire precautions and about environmental health, and the operational policy will have envisaged some sort of procedure for the safety of medicines and the security of the property.

None of these issues are trivial; procedures may often have been proposed which are unacceptable because they restrict unnecessarily the range of opportunities and experiences open to the people using the service, but the goal of safety is not inappropriate in a staffed housing service. In addition, working out acceptable solutions jointly with specialist advisers can be used as a way of gaining their commitment to the aims of the project and to produce the relevant components of staff induction training.

An effective procedure in the event of fire is often an important component in negotiating unobtrusive built-in fire precautions. The basic decision the procedure needs to address is under what circumstances staff should try to fight the fire with equipment in the property and when they should evacuate the premises and call the Fire Brigade. Practical demonstrations of equipment and evacuation are easily arranged as part of staff training and demonstrate the staff's commitment to the fire safety adviser.

The procedure for environmental health issues is likely to consist of guidance on food preparation and storage, hygiene in cleaning and agency policy on smoking. For security the holding of keys and the nomination of one person on duty as the person responsible for security is a simple step but the main practical issue of concern is likely to be what a member of staff alone on duty at night should do if they believe that someone is on the property.

For the safety of medicines, a clear procedure is needed which governs the prescription, storage, giving and recording of medicines. Example 6.1 is such a procedure.

## Preparing People for the Move

The move from hospital or home to staffed housing is likely to be a major transition to which anyone would have difficulty adjusting. Anxiety in advance of the move; the disruption of long-established ways of doing things; the loss of relationships, valued possessions and the treasured associations of places and things; and the adjustment to new circumstances are all likely sources of stress. Recognising this leads naturally to thinking about the preparation needed by the people to be served before they move to their new homes.

In planning how best to prepare each individual for the move, it is however important to weigh up the costs and benefits of lengthy preparation. One way of



*Example 6.1*

**Procedure for safe handling of medicines**

1. Prescriptions will be copied onto a treatment card by the staff team-leader in the family-doctor's presence. Prescriptions will be obtained from a local pharmacy.
2. Medicines will be kept in the medicine cupboard which will be locked at all times when not in use. A member of staff on duty will always be nominated as responsible for the security of and giving of medicines.
3. Medicines will be individually labelled with the name of the person, name of medicine, strength of medicine and how often to be given. Labels will be written in plain English without abbreviations such as TDS etc.
4. External applications will be stored separately in a locked cupboard.
5. All the care staff will administer medicines and external applications as prescribed. Medicine will be checked, given and recorded to one individual at a time. A member of staff giving medicines will (1) **check** the name of the client, the name and strength of the medicine and how often it is to be given as recorded on the bottle against the treatment card for the individual concerned, (2) **administer** the medicine to the client and (3) **record** that the medicine has been given by initialling a weekly medicine chart on the inside of the medicine cupboard door.

*This is based on the assumption that staff will give most medicines. An alternative would be to use the District Nursing service where the medicines concerned are dangerous or the procedures particularly skilled (for example, giving a daily insulin injection). The procedure suggested can still be used, but fewer medicines will be needed on the premises and the district nurse can give staff guidance from day-to-day.*

conceptualising re-settlement is as a process of gradual transition, in which the old setting is transformed step-by-step into as near as possible a copy of the new setting so that, when the transfer actually takes place, it is just one more in a series of small steps. However another way is to see re-settlement as rescue from a damaging setting and to expend little effort in trying to change it before moving the person to their new home where, since the change will have been much more dramatic, more help will be needed to achieve successful adjustment.

Which of these approaches to use depends on a judgment about the individual person's ability to understand and cope with the different sources of stress and about the characteristics of the old and new settings. If someone understands a future date of transfer and if the old setting can provide reassurance and help to get ready, then telling the person as soon as possible may make sense; but if they are likely to believe that the move is imminent, or if the old setting feeds their anxiety about the new, then it may be fairer only to tell them when practical progress can be made. This is particularly important if there is any risk that the service agency will end up delaying transfer.

Similarly, 'pre-discharge training' in an institution may be helpful in so far as it approximates the real situation the individual will find themselves in. But if, as is often the case, the institution can only provide a pale imitation of real life or worse a warped or bizarre kind of experience (and the intractability of institutions in this respect is, after all, one reason why they are being abandoned as a model of care), or if the person concerned and the staff who work with them believes that they will not move to a new home unless in some sense they pass a pre-discharge test, then it may be easier on the individual and the staff in the old setting to let things carry on as they always have and to tackle unmet needs in the new home. Sending new staff to work in the institutional setting with the people they will serve may also frighten them away or acclimatise them to unacceptable practices,



apart from the management problems it causes the old setting and its staff.

Bearing this dichotomy in mind, there are three tasks for the project organisers. First they have to supplement the initial sketch of each person's needs carried out in project definition and get to know each individual well enough to make the transition as smooth as possible. Second they have to negotiate and supervise whatever preparation is decided upon in the old setting; and third, they have to plan each person's reception in their new home and tie this in with the induction training of staff.

### *Getting to know Each Individual*

It was pointed out in Chapter 2 that, once a prospective resident of the service has been identified and visited, it is important to maintain contact with them as the project is brought to fruition. Since the experience of people with mental handicaps, their families and staff is often one of unfulfilled undertakings and not really knowing what is planned by the service at agency level, this contact is principally to reassure the individual, their family and the staff currently working with them that the service still intends to provide a new home. Note that it is the continuing commitment of the service that needs communicating - people may not need to share in the disappointments and setbacks experienced by the project organisers along the way.

As the prospect of moving home becomes a practical reality, the outline information collected about each individual to be served needs to be supplemented. When the person arrives to take up residence in their new home, the staff who work with them will need to be able to respond effectively to their most pressing needs and to minimise the stress of transition by keeping links with parts of the person's past from which they gain comfort or reassurance.

The main actor in getting to know each person should be the team leader of the group of staff working with

that individual. Where the project organisers opt for a gradualist model of transition they may employ care staff sufficiently long in advance of the availability of new homes that they can work with the people to be served in the institutions where they currently live (or, though this is rarer, with the families where people are still living at home). But whether or not front-line care staff get to know people well before the move, it is certain that the team leader needs to know each person well enough to guide staff through the early weeks of operation of the new service. A series of visits of increasing frequency as the date of transfer approaches provide not only an opportunity to reassure everyone of continued progress but also the opportunity for the team leader to become someone who will bridge the old and new settings.

Within the general context of getting to know each other, three specific kinds of knowledge are especially useful. Augmenting the picture of the individual's life history and the situation in which they now find themselves can provide an important backdrop against which care staff develop their tolerance of individual problems; many staff will have no experience of traditional services and may not realise the extent of deprivation suffered by the people they serve. This does not have to be framed in a way which is punitive towards staff in the old setting - indeed it is important for staff to see that everyone (including families) can start with good intentions and still become victims of the system of care.

The second area of information needed is a detailed practical grasp of urgent unmet needs and the beginnings of a strategy for coping with these needs from the first day. Some needs will be for services or resources - people who have lived in poor quality services will probably need clothing, basic personal possessions and may need spectacles, dental treatment or any of the other services not well provided in traditional services. Some needs will include effective compensatory help for a lack of ability and, linked with this, for rapid skill development - in areas such as continence and eating skills where it is often



possible to make substantial progress very quickly given some reasonably competent teaching. Some needs may also relate to behavioural problems or difficulties the person has. Here too the team leader needs to be developing a strategy for weakening and replacing problem behaviour over time, but it is even more important that a specific way of managing the difficulty from Day One has been constructed ready for use in staff training.

Part of the thinking through of short- and longer-term strategies for working with individuals is finding out what methods for communicating and teaching work best with each individual. It is not really necessary to do this in any formal sense so long as the team leader is skilled enough to to take account of the level of implicit cueing present in informal opportunities.

The third area of knowledge needed about each individual destined to move to the new service is to identify those possessions, experiences and relationships which the individual seems particularly attached to and to plan to ensure that, as far as possible, these are maintained in the person's new home. Where people are living in relatively impoverished surroundings it may take some care to establish what, if anything, there is to keep. It seems a reasonable assumption that the fewer attachments a person has the more they may be valued and such care is therefore well justified.

In the gradualist model of transfer, where the aim is to carry out extensive pre-discharge preparation, this process of getting to know the individual can be tied in both with the initial process of establishing need described in Chapter 2 and with setting up an Individual Programme Planning system like that described in Chapter 8.

### *Preparation in the 'Old' Setting*

Apart from getting to know each person as an individual, preparation in their existing residential setting needs to include telling the person about the move and involving them in choices about their new life. How much

this can be done depends on the form service development takes and the ability of staff to present choices in a meaningful way. Where a new home is being provided in response to the needs of one or a few people at a time and where their need to get out of their existing home is not too urgent, it should be possible to involve most people effectively in choosing where and how they live. Where the process is more hurried or the severity of a person's disability defeats staff attempts to present choices it is likely to be much more difficult to involve the person in much more than choosing items to take with them.

For many people, it will require some ingenuity on the part of the project organisers to tell them of their impending move. Where explanation is ineffective, it may be possible to give the individual an album of photographs of the new home or take them to visit it on one or more occasions - even to stay overnight (although perhaps only if it is then practicable to respond to a clearly expressed desire to stay in the new setting from that moment on).

As noted already, preparation in the old setting can include some sort of rehabilitation programme. Where the old setting is the family home, no such programme is usually suggested, in recognition no doubt of the complexity of the family environment, the different goals it must address and the stresses it has already borne. Instead the process of preparation is undertaken by gradually increasing the frequency and duration of visits to the new home. This option is readily available where the old setting is a residential care establishment and the same reasons apply; the extent to which the idea of pre-discharge training in these places is favoured raises the issue of whether the real purpose of training *in situ* is to rationalise the purpose of the institution.

As the actual day of the move approaches attention has to be given to practical details like packing (the person may have no suitcases), the means of transport to the new setting and who will accompany the individual (clearly a car is less obtrusive than a minibus or ambulance) and



practical guidance and help from staff in the old setting about current medicines and any other issues.

*Reception in the 'New' Setting*

Preparatory visits and the actual move itself need to be planned so that the individual handicapped person has something to do on arrival - some feature of the new setting which enables them to participate in a new kind of activity instead of standing around while other people enthuse. Valued personal possessions can be transferred on each visit and opportunities can be arranged for the person to participate in activities like preparing food or drinks, using household equipment (vacuum cleaner, food mixer) or the garden (pegging out washing). For people with limited receptive and expressive language these practical experiences may do much more to communicate the nature of the choice between old and new settings than any amount of explanation.

Similarly, where families or friends are in contact or want to establish contact again, this will be easier in the staffed housing service and the first visits can also include meetings. Some of these might also usefully be structured around activities (perhaps with staff help) where the customary activity of sitting and talking or drinking is hard to maintain for long.

A natural extension of this is to help the handicapped individual to host visits from friends in their previous residential setting; this is likely to be easier to do than to make return visits if it proves difficult to explain the difference between a return visit and transfer back.

**Organisation and Deployment of Staff**

At some point, the team leader responsible for a group of staff will work out a duty rota. This will constrain the way staff work in many ways and it is therefore important to construct a method of staff allocation that takes account of the demands of the model of care. It is

also important that this is done at the outset, so that staff have clear expectations from the start of what is likely to be their schedule of work.

There are six criteria to be considered in working out the deployment of staff:

1. the times which need to staffed
2. the extent to which staff work with each other
3. the provision of adequate rest time
4. the use of a weekly staff meeting
5. on-call arrangements
6. flexibility and responsiveness of the allocation both to the needs of staff and the people served

Two illustrative examples of staff allocation which take these criteria into account are given in Appendix 1.

The number of staff needed at each time throughout the day and night will already have been considered in the planning of the service, initially in outline to secure resources but then in more detail as the project organisers find out what are the needs of the individual people to be served. The main issues here have already been referred to in Chapter 5; the length of the day, night staffing arrangements, whether the people served go out during the weekdays (so that cover is only needed for occasional sickness or holidays) and what is the minimum number of staff needed when the people served are at home.

The way individual members of staff are allocated to duties within this overall framework has an impact on the way they work together. If staff work opposing shifts (so that the staff are effectively divided into two separate groups that remain the same) as in many traditional residential settings, variation in working practices will be encouraged and competition between shifts will result. The alternative is to arrange individual duties so that staff routinely work with each other (i.e. all staff work with all other staff, including any night staff), typically by mixing



early and late duties each week and (where there are waking night staff) providing cover for holidays by staff on days by occasionally bringing in someone who usually works nights, and *vice versa.*

A second aspect of this issue is that senior care staff will need consciously to plan opportunities to work regularly with their basic-grade colleagues, to maintain their own direct-care skills, to get immediate feedback on how well the staff team is able to support the people it serves and to model more skilled performance for other staff. Where a member of staff is nominated as deputy they will need to spend part of their week working with the team leader for the same reasons. Since senior staff will find it difficult enough to resist other administrative demands on their time, these periods of working with other staff should be planned in on the staff rota rather than fitted in when circumstances permit.

These are not just general principles: they apply at a personal level in allocating individual staff to particular duties to make up the particular mix of strengths and needs among the staff on duty at any time. Some staff will certainly need more support than others, there will be individual differences in the different parts of the staff role (some will be much more skilled at first in housecraft or teaching or helping people access new experiences in the community) and some staff will not work well together.

The third criterion to be met by the staff rota is that staff have enough time off, both during their work and between weeks. Although there will be occasions when staff have to work long hours, or too many days at a stretch, it is obviously important to avoid over-loading individuals so that their private life is unmanageable and they are unable to recover between shifts. In this context it is worth noting that the staff task in high-quality services can be considerably more demanding than in traditional forms of residential care.

The rota should be based on the number of staff whole time equivalents, excluding the holiday entitlement, to reflect the number of staff really available to work

accurately. For example, a team of 10 staff, made up of two senior staff entitled to seven weeks holiday and eight basic-grade staff entitled to six weeks, is entitled to 62 weeks holiday a year. Dividing by 52 weeks means that for 10 weeks of the year two staff will be on holiday and for 42 weeks of the year one staff will be on holiday. The staff rota therefore needs to be based on nine staff being available rather than 10, and staff holidays need to be carefully spread through the year.

Since the model of care in staffed housing really requires that staff participate with the people they serve in meals and breaks, arrangements need to be made for staff to take breaks at other times. One way of doing this is to allow meal and break times to be taken at the end of the shift so that, if people wish, they can leave at the end of their shift taking their 'break' time with them. This has the effect of paying staff for the whole time they are on duty without denying them naturally occurring breaks at the same time as the people served, while preserving their own break time.

Regular staff meetings which all staff attend also need to be taken into account in constructing staff allocation. Ensuring everyone's attendance may involve scheduling everyone as on duty for that part of the day, or it may mean operating systems of paying back time, sharing working hours over a number of weeks or paying overtime rates for some people to attend the meeting.

The basic-grade members of the team of staff supporting a small group of people with severe and profound mental handicaps in one or a few houses or flats will need considerable support, especially in the early days of a new programme. They will face many new situations and will probably spend a greater proportion of their time unsupervised than would be the case in large residential facilities, and they will not have other hospital wards next door from which to get advice and help. On-call arrangements are therefore extremely important both to ensure programme quality and the confidence of staff.

In most cases all that is required is advice given over the telephone; but there will be occasions where the



presence of experienced senior staff is required quickly. It is therefore important that senior senior staff live nearby and are accessible. Since there are likely to be particular periods when the need for outside help is heavy (at the beginning, when someone is ill, at some stages during work to help an individual manage their problem behaviour) some plans need to be made for sharing the on-call duty. Where there are a number of services or staff teams in a locality each can support the others to some extent; alternatively, it may be possible to use community support staff. Whatever arrangements are made have to be sustainable over time and have to avoid strangers giving advice about situations, people and service goals with which they are unfamiliar.

Finally, no staff rota can remain fixed if the staff are to respond to the changing needs of the people they serve. The system of allocating staff therefore needs to be sufficiently flexible that it can be adjusted to cope with new demands either from the people served or from staff themselves, without degenerating into an ad hoc or last minute schedule that gives no-one enough notice of their duties and ignores some of the considerations already discussed.

In practical terms this means establishing the basic framework and working out actual duties for a period ahead (about six weeks) at regular intervals of no less than two weeks, so that staff allocation is planned six weeks ahead of implementation. It also means using the option created in the job description to vary duty times to meet individual needs, so that no-one assumes through custom and practice that these times cannot be changed. Since staff will need to shape the duty rota themselves, in order to cope with their own needs, some mechanism needs to be created to do this. If a book of staff duties is kept (see Chapter 7) with rotas planned six weeks ahead, staff can enter their requests against each rota. This maximises the opportunity for staff to volunteer reciprocal arrangements and maintains the team leader's option to ensure the desired mix of staff.

**Further Reading**

Brost M M, Johnson T Z, Wagner L and Deprey R K (1982) *Getting to know you: one approach to service assessment and planning for individuals with disabilities*. Madison: Wisconsin Coalition for Advocacy.

# 7. Staff training

Staff training is not a short-term activity in a high-quality service; it is an integral part of the management of the service. It starts with the induction training of the team leader and then of the staff team in advance of the service commencing operation. The aim of this induction training is to achieve the level of competence and confidence among the staff to provide a high-quality service from the moment the first person arrives at the new home. However, bringing the staff team to a level of competence from which they can securely develop the quality of service they provide, takes more than a few weeks and must involve hands-on training in the real situation with the people served. The induction training therefore leads directly on to a period of several months in which the full range of help for the people served is introduced and established, from the helpfulness of staff interaction patterns to the organisation of the service around individual programme plans.

Even then the process of continuing development of staff skills and knowledge continues through the medium of the participative management approach and the review of accomplishments described in Chapter 11 (Quality Assurance). The elements of the induction training, augmented to take account of more sophisticated ways of working developed by staff, are re-presented on a continuous cycle of refresher training for staff in post and induction training for new members of staff.

The integration of in-service training and the day-to-day operation of the service in this way is still relatively unusual and may need to be justified against two commonly held alternative views. One of these is that all that is really needed is to find the right blend or type of housing, and operational policy and staff orientation and high-quality care will in some sense 'naturally' result. This claim that "all that is really needed is for people to *care*" (or sometimes "*really* care") is in part a reaction

against what is seen as the way in which the medical model has represented mental handicap as a biomedical phenomenon requiring technical, specialised responses to the exclusion of common humanity.

There is, however, little empirical support for this view; indeed it is the failure of attempts which change only the suggested service characteristics to have a sufficient or lasting impact on the quality of life of the people served, that has led to increased focus on staff training. This claim also conveniently ignores the extent to which people with severe and profound mental handicaps do have problems which need sophisticated solutions (whether biomedical or psychological), albeit delivered in ways consistent with and enhancing of the personal lifestyle of the handicapped person.

The second objection to heavy investment in in-service training is that caring for people with mental handicaps is a professional task and the appropriate strategy to achieve an effective service is to appoint people with the right professional background. This is an easier objection to dispose of in Britain. First, there does not appear to be any 'right' profession and there is very slow progress towards creating one. Social work training continues to leave very large gaps in knowledge and practical skill at working in sophisticated ways with people who have major, chronic disabilities. Nurse training in mental handicap, despite a new syllabus, remains dominated by the traditional hospital model of care.

Second, since the staffed housing model of care is new, the professional training available is largely carried out in traditional kinds of service and the teaching is done by people whose only experience is in that kind of service. Third, none of the professional groups involved in mental handicap is yet producing practitioners competent to use the more advanced methods of teaching or enabling the participation of people with severe and profound mental handicaps (although teachers are the group who have made most progress). Fourth, the majority of care staff are unqualified and this is likely to remain so because of the cost of training everyone for



three years and paying them more, and because of the lack of evidence that professionally trained staff deliver care differently from unqualified staff with good in-service training or experience.

While low pay, poor status and limited career prospects of staff are serious obstacles to developing staffed housing for mentally handicapped people, the four reasons given above justify a strong focus on in-service training, meshed together with its day-to-day operation, as the main intervention to secure a good staffed housing service.

## Induction Training

For a new staff team induction training can be planned for the whole group together over the two or three weeks before the first people move in. Working together as a group in this period is an important part of the training experience. Since the team leader, and perhaps their deputy, need to be seen by other members of the team as leaders and teachers, they need to play a part in the training. Therefore they must be appointed before the staff team and involved in constructing the induction training (as well as in other important issues like staff appointments, liaison with the people served, their families and new neighbours).

Although appointed earlier and with more expertise to start with, team leaders and their deputies also have training needs. Where enough staff teams are being set up at the same time, it may be possible to arrange induction training on a cascade model, training all senior care staff as a group in an enhanced and adapted version of the programme for the front-line staff before expecting them to take the lead in repeating the programme with their own teams.

Where this is not possible because the numbers are too few, a different model - apprenticeship - needs to be used. In this the team leader joins the project organisers (preferably literally by moving into their offices as a

main base) not only in working on other aspects of commissioning the new service but also in gaining expertise in training and in aspects of the direct care of the people served which are new or unfamiliar. Since it is important for the new team leader to feel confident and supported by the project organisers, these tasks need to be seen as developing shared competence to train staff rather than as placing the whole burden on the team leader.

Once some services are operational, they can be used to provide hands-on direct-care experience for senior care staff. In practice this will be limited by the desire to avoid intruding upon the lives of people in the existing services and by achieving the required balance between drawing on other people's experience and feeling that there is scope for individual initiative.

As the project comes to fruition, the group of people who have acted as project organisers come under increasing pressure of work to coordinate the different strands of activity involved. Often, they search for a way of buying-in the training expertise needed, rationalising this course of action by saying that they have too much to do and that they do not have the necessary training or direct-care skills. This may in any case be an unrealistic strategy because there are very few people with good skills in these areas. Expensive and attractive training packages often turn out only to cover material in quite modest depth. There are also several reasons why, as a matter of principle, the project organisers should play a major role in training their staff. The major issue in any training is the effectiveness with which people transfer what they have learned from the teaching situation to their real work: effective transfer requires, in practice, a great deal of consistency between the training and work situations including the sources of reward and motivation and the very gradual fading of assistance as people become more competent. The implications of this are that the training needs to be tailored to match the work situation, the training relationship needs to bridge the induction/work divide and staff need to see the project



organisers (their future managers) as sources of leadership and motivation.

In practice this is likely to be best achieved where the project organisers do a large part of the training (perhaps with some help). By designing and carrying out the training themselves they can ensure that it meshes effectively with the service outcomes they want; they can check the consistency of what they say they want the service to do in the training sessions with how they behave as managers; and they can convince staff that they know what they are talking about and are committed to helping staff achieve service objectives.

Where help can be found, particularly help with training methods or hands-on experience of the new patterns of services being developed, it is obviously a valuable resource to be used. But it remains important not to 'sub-contract out' important areas, to avoid the risk that those areas are seen as optional extras which are not really based on or integrated with the rest of the model of care.

## Constructing an Induction Programme

Since there is little empirical evidence with which to choose between alternatives, there are a wide range of options in constructing an induction programme, in terms of the content to be covered, how much of each topic is presented in the induction training instead of after the arrival of the first people to be served, the balance between knowledge - or attitude - directed training and practical training, the teaching methods used and the timetabling and organisational aspects. The design of any programme will be based on a set of assumptions about training, and the following seven principles may be especially relevant.

1. The first guiding principle is that the most effective way of building practical competence is through hands-on training in real-life situations. There is ample evidence that classroom-format teaching is effective at

changing the behaviour of answering questions in tests but not at changing what people actually do; for this real practice under skilled supervision is much more effective.

2. Staff teamwork and cohesiveness will be more effective if team members become as competent as each other. An important implication of this is a strategy of maximising opportunities for staff learning in areas where they are weaker than their colleagues. This means resisting the temptation to let the good cooks cook and the good teachers teach so that those with most to learn about cooking (or teaching, or anything) get most practice during the induction training.

3. Attitudes are changed more effectively by requiring staff behaviour (the way they give practical expression to their views) to imitate the standard shown by leaders or teachers, than by lecturing them about the desirability or rightness of certain views. This is particularly important where most or all staff have no experience of traditional services, and where an extended presentation of the problems of such services and the principle of normalisation may frighten people off or bury the message in jargon.

4. A major use of the knowledge content of training is in staff explaining what they are doing to other staff, service consumers, managers or members of the public. Staff will often be called upon to justify the service they provide; why it is necessary to help people shop for themselves or open bank accounts or use a local dentist. The fourth principle is that it is likely to be much easier to train for this competence using a role-played format, rather than to rely on paper and pencil tests and hope that people generalise to the real-life setting.

5. In the overall presentation of training, it is better to establish the importance of the general organisation of the household to facilitate participation by the people served before introducing specialised interventions (like precision-teaching). This is to avoid creating the impression that the life of the people served can be divided into 'programmed' (busy, focused, purposeful)



periods against an 'unprogrammed' (wasted, unfocused, doing nothing) backdrop.

6. Where methods or interventions are taught that have been badly used in the past and are particularly powerful (eg some behaviour modification techniques), and which therefore present a riskier threat to the principles on which the service is based than novel or weak methods, these should be taught as responses to individual need rather than as sets of general principles staff can apply whenever they choose. This is one aspect of operationalising the 'least restrictive alternative' principle; staff are taught general methods of helping people using positive reinforcement and extinction, but are only taught more complex or restrictive interventions at this stage if they are essential to meet the urgent needs of particular individuals.

7. Finally, the timetabling of the training should provide variety between types of content and teaching method, and the sequence of content should, as far as possible, require staff to practise material presented earlier in each subsequent session, and to build cumulatively the inter-relationships between different aspects of work rather than expect staff to infer them after the induction period.

### Format of the Induction Programme

A sample induction training programme timetable is shown in Example 7.1. It reflects a compromise between practical necessities and the principles listed above. Some areas (such as Individual Programme Planning) are left out, to be dealt with later, while others (such as language and communication) would be better integrated into the other sessions in the same way as behavioural principles.

*Example 7.1*

**Induction training timetable**

| Day | Morning session | Afternoon session |
|---|---|---|
| 1 | Introduction<br>Idea of participation | Housekeeping<br>Planning meals |
| 2 | Shopping | Cleaning and Housework |
| 3 | Safety procedures<br>Personnel issues<br>Handling money | Laundry and Gardening |
| 4 | Developing helpful interactions | Developing helpful interactions |
| 5 | Introduction to the people to be served and their families | Communication<br>Who's who locally<br>Meeting colleagues |
| 6 | Teaching: fuzzies and performances | Setting goals<br>Assessment |
| 7 | Breaking tasks down | Structured teaching |
| 8 | Meeting immediate needs | Physical care |
| 9 | Organising the day | Open afternoon for visitors |
| 10 | Physical care<br>Keeping quality high | Operational policy and review |



Any programme needs to include four types of session. Core themes are presented in sessions which involve short presentations by two or three project organisers together with various practical exercises supervised by the presenters. A second type of session imparts information - about the people served, the local community, relevant service agencies and various operational procedures. In many of these sessions managers or advisers can be included in the teaching team. In Example 7.1, the session dealing with the people served was led by the staff team leader (who had got to know the individuals concerned as described earlier in this chapter); while the deputy led the session on local contacts. The third kind of session is group discussion in which staff, led by the team leader, decide on some of the practical arrangements to receive the first people coming to live in the house. Finally, time needs to be set aside for staff to put the results of these discussions into practice, getting the house ready for its first occupants. If all the training is done in the house itself in the two weeks before the first people move in, staff can cook meals, do housework, repair poor workmanship and work out where provisions and equipment will be stored.

## Content of the Induction Programme

The remainder of this chapter deals with the core content of induction training needed to establish the model of care described in more detail in the remaining chapters. The emphasis here is on the training approach to use with new staff rather than the elegance of the ideas or the completeness of the issues covered. The topics dealt with below are:

1. Introducing the training to staff
2. The idea of participation
3 Housekeeping
4. Developing helpful interactions

5. The introduction to the people to be served and their families

6. The use of job-aids and reminders to organise staff support

Teaching is not dealt with in detail here because there are readily-available teaching materials (to which reference is made in Chapter 9).

*Introducing the Training to Staff*

The main decision to make about introducing the training to staff is what balance to strike in presenting the philosophy of the project to avoid the risk of overwhelming people new to the issues. Even if no special introduction to mental handicap or the philosophy is given staff will have already been given the operational policy and guidelines to candidates when appointed. The main aim should be to represent the people served as ordinary people coming from an impoverished background and to try to avoid what for most staff are new details of individual disabilities or the problems of mental handicap services obscuring this approach. Personal details can be provided later in the induction training and, several months after the induction period, individual staff should be given the opportunity to visit traditional kinds of mental handicap service in the company of a project organiser on a visit concerned with another scheme. Similarly, opportunities should be provided later for staff to attend normalisation and Program Analysis of Service Systems (PASS) workshops.

It is important that the project organisers should try to make their own contributions to the whole programme consistent with normalisation, using discussion to bring out the implications of this approach and of any other over-riding principles (such as the use of a behavioural perspective). Similarly, the language used to describe the service and the people served should be consistent with this approach and every effort made to correct inappropriate comments or assumptions throughout the



workshop. Some of these issues can perhaps be helpfully summarised as a list of dos and don'ts (Example 7.2) to which attention can be drawn at relevant points and which can be given to staff as a handout.

*The Idea of Participation*

The aim of this session is primarily to define participation in relevant activity as the major yardstick of service quality, and to teach staff to distinguish between meaningful participation, on the one hand, and inactivity or behaviour which interferes with participation on the other. In addition the session is used to introduce the importance of individual choice and control in maintaining interest in activity (i.e. part of the value of intrinsic versus extrinsic reinforcement). The format of the session could be a presentation by two project organisers interspersed with short discussion points. Slides should be used to illustrate the presentation, while key points of the presentation and discussion should be written up on flip-charts.

The content of the session is summarised in the following 12 points.

1. Typically, everyone spends most of their time participating in activities rather than doing nothing. Active participation in a wide range of tasks and situations is widely thought to be an important indicator of mental and physical well-being. Even when apparently 'doing nothing' people are often doing something - watching television, reading or looking at the scenery on a walk, for example.

2. Ideally, people participate through choice and part of the satisfaction they derive from the activity comes from their having chosen when and where and how to do it. When one task becomes less stimulating, people often choose another with renewed interest. But even where activities have to be done - like housework or shopping or going to work - people derive satisfaction from completing them ('getting the job done') and the variety

*Example 7.2*

## Handout for staff on 'Dos and Don'ts'

| | |
|---|---|
| 1. Talking to individuals | |
| Don't talk to adults as if they were children | Do talk to the person as you would to anyone else of the same age and sex |
| Don't be rude, order people about or make fun of them - even in jest | Do talk to people politely |
| Don't raise your voice unnecessarily | Do talk in the same volume of voice as you would with other people in the same situation |
| Don't forget to talk to people when helping them - use the ordinary social pleasantries | Do talk to the individual about what is happening or what you are doing, even if you are not sure they understand |
| 2. Talking about an individual | |
| Don't refer to someone in a negative way by highlighting their problem or disability | Do talk about each person with care and respect, representing them in a positive light |
| Don't discuss someone in front of them as if they weren't there | Do involve the individual in discussion as much as you can, and talk about their capabilities and needs |
| Don't refer to some by clinical category ('he's a spastic') | Do use clinical information when it helps a proper discussion of strengths and needs |



## Handout for staff on 'Dos and Don'ts' (continued)

| | |
|---|---|
| 3. Personal appearance | |
| Don't impose hairstyles or dress people in clothes inappropriate for their age or long out of fashion | Do encourage people to dress and wear their hair as fashionably as others of the same age |
| Don't neglect a person's needs for cosmetic treatment | Do help people who need them get and use dentures, support clothing, treatment for skin complaints etc. |
| Don't neglect individual diet and exercise | Do encourage good diet and exercise, leading to attractive appearance |
| Don't make people hold hands in the street | Do help people conduct themselves in public like other people of the same age |
| 4. Personal possessions and pursuits | |
| Don't encourage adults to acquire childish possessions | Do encourage people to acquire and use possessions which are appropriate to their age |
| Don't restrict possessions to those which are cheap and which lack technological sophistication | Do help people look after their property and use sophisticated equipment |
| Don't restrict people to mix only with other people with mental handicaps in specially organised events | Do help to develop independent leisure activities including some which involve joining in with other people |
| Don't routinely take decisions for people | Do help people make good decisions or choices for themselves and do attend to their decisions, choices or preferences |

of different tasks that have to be done in a typical day is itself important in making the difference between a day that is busy and interesting and a day that is stale and boring.

3. One of the most important achievements of the service is therefore, how much the people served participate in all the usual activities of daily life: the amount of time they spend in these activities as opposed to doing nothing, the variety and importance of the activities they join in and the extent to which they choose what to do.

4. Therefore the job of the staff in the service is to help people join in all the self-care, household, recreational, social and leisure activities that people might want to do or that arise naturally in the home and local community.

5. Some of the people the staff team will support will have more skills in certain areas than in others; some may be generally more able than others; some will be very handicapped indeed. The goal remains the same for everyone. People who need more help to choose what to do or to join in fully will get this help from staff - no matter how much help this might be.

6. Note the difference between helping someone to join in the activity and inadvertently cutting them out of it, by doing it for them or by giving too much help.

*7. At this point show about 20 slides of people - not necessarily just people with mental handicaps - participating in activity or doing nothing. Include a wide range of ordinary activities and situations and include slides which show people participating only with the help of another person. Use adult materials and contexts. Question staff about whether people are participating and use their answers to re-state the distinction.*

8. In deciding whether people are participating, it is useful to think of three kinds of participation:

8.1 interacting with another person - talking or listening to them or paying attention to what they do



8.2 using materials or equipment (not just holding them or carrying them), such as a kitchen blender or a vacuum cleaner or a compact-disc player

8.3 taking part in a group activity such as watching the ball and running after it in a game of football

*Show more slides giving several examples of each of these categories.*

9. Lack of participation can be seen as being one of four kinds of situation:

9.1 doing nothing, dozing, just walking around (including walking around just carrying something)

9.2 repeating the same thing over and over again (rocking, talking to no one in particular, fiddling with clothing or hair)

9.3 doing something disruptive (losing one's temper, knocking things over)

9.4 passively doing what you are told or allowing someone to do something to you without joining in (having your teeth cleaned for you or being dressed)

*10. Illustrate these kinds of lack of participation with slides (trying to use slides of people who are not mentally handicapped as well). Then present another 20 or so slides asking people to say whether the people shown are participating or not. Include about three-quarters of the slides showing participation with some kind of help.*

11. This distinction between active participation and disengagement is therefore not only a good measure of the quality of life of the people served but also of how well the staff team is doing its job. In thinking about every aspect of getting the service going it is important to work out how people can be involved in each kind of activity and how to give them the help they need to make good choices and join in effectively.

*12. In reviewing the topic and answering questions it is likely that people will ask about the prevalence of problem behaviour. Use this opportunity to say that the aim is to promote participation by giving people a wide range of choices and activities and by encouraging and helping them join in, rather than by trying to stop problem behaviour.*

*Housekeeping*

This topic deals with:

1. shopping and the preparation and organising of meals
2. cleaning and tidying around the house
3. laundry and clothes care
4. gardening

The aim of these sessions is to work out a clear framework for getting everything done from Day One, recognising that these arrangements will change soon as the people coming to live in the house develop their own preferences. In line with the previous session, all the housekeeping is planned on the basis of helping people do the task rather than doing it for them or instead of them.

The format of these sessions should be a group discussion led by the senior care staff with one or two of the project organisers joining in. In preparation, lists of possible ideas (e.g. possible meals) need to be prepared to help generate discussion and focus attention on the decisions to be made. During the discussion, staff generate and discuss possible arrangements; the role of the session leader is to prompt when issues of principle apply and if necessary to rule out some ideas altogether. The arrangements are written up on a flip chart as the discussion proceeds.

The issues addressed in each of the four sessions are summarised below, with illustrations of the kind of decisions which might be reached.



*Meals and Shopping*

1. The kind of meals to start with (eg main meal in the evening except on Sunday; a continental breakfast in the week). Staff plan menus for the two weeks of the induction training. During the discussion the criterion of maximising opportunities for participation and choice is used to decide appropriate arrangements and types of menu.
2. Staff generate shopping lists to stock the kitchen and to allow them to cook meals for themselves through the induction training period. Apart from providing the opportunity for staff to work cooperatively together, these meals are used to begin the process of bringing everyone up to a good standard of cooking.
3. Taking the first few meals as examples, staff discuss how to break down meal preparation into its different components with a view to involving people in those parts of the task they could do, even if there are others currently too difficult. *Note that this is the first introduction of the idea of task analysis but it is introduced in relation to joining in activities people can already do rather than teaching new behaviour.*
4. Similarly, the actual conduct of a meal is discussed to draw out several specific goals. The first of these is the aim of developing making choices among the people served, and particularly of taking control (not asking permission all the time). Second is the aim of mutual cooperation at the table without developing status differentials (i.e. not always asking staff to pass condiments or always asking the people served). Third is the aim of organising the meal so that everyone sits down to it together, avoiding periods either before or after the meal when the people served have nothing to do while staff busy themselves or talk to each other.
5. Finally, the same process of working out how to organise the activity to encourage participation by the people served is applied to clearing away and washing up after a meal.

*Cleaning and Tidying Up*

1. The first part of the discussion should deal with how often different areas should be cleaned and what sort of standard to aim for: this is not an unimportant issue as the staff team will have very different ideas and some team members, with less experience of running a home, will need to learn the best methods of cleaning.
2. Specific teaching is done (in this case with a specialist adviser) on methods of cleaning sinks, baths and toilets, the care of floor surfaces and stain removal.
3. In discussing how to structure cleaning activities so that the people served do them with help, rather than have them done by staff, it is emphasised that the traditional perception of housework - that it is something to do as quickly as possible to make time for other tasks - need not apply until there is too much interesting activity with which to fill the day. Thus, the primary aim should be to do the housework in the way which maximises the opportunities for people to choose what to do and to do it with as much help as they need, even if this is not the quickest way.

*Laundry*

1. Two basic decisions about laundry might arise from the first discussion. It needs to be agreed that clothes will not be labelled with people's names - that if some confusion might arise (eg over stretch tights) a tiny marker of coloured thread could be sewn on to the item. Second, laundry and ironing can be done family-style rather than keeping each individual's clothing separate, but spread throughout the week rather than all done at the same time.
2. Subsequently, staff can outline plans for involving each person in each type of laundry arrangement - handwashing, using a washing machine at home and using a launderette.



*Gardening*

The garden is as rich a source of activity as any housework task and it has the advantage that analyses of the different tasks needed already exist in books. Rather than reach a group consensus about the care and development of the garden, one person can be nominated by the group to coordinate work. The common activities can be discussed to illustrate how to break them into components to make them available for participation.

*Developing Helpful Interactions*

Having discussed all the basic household routines in terms of how best to organise them to facilitate participation by the people served, the next session deals with the way interaction between staff and the people served could help or hinder effective participation. The aim of this session is to teach staff:

1. To deploy their attention contingent on adaptive behaviour
2. To provide only as much help as needed
3. To develop more skill by the techniques of reinforcing successive approximations (shaping) and fading help.

The format used with this topic could be a series of presentations and demonstrations by two or three project organisers (sometimes including the team leader) followed by role-play by staff. Checklists and flip-charts should be used to structure discussion and to get staff used to the idea of giving each other feedback.

The content of these sessions is covered in many introductory workshops on behavioural intervention and should be well within the competence of any psychologist to plan. The description that follows is therefore intended principally to convey the kind of language used and examples given, and the exercises involved.

*Facilitating Participation*

1. For most people most of the time the best way of understanding what they do is to look at what happens before and after they do it. This is sometimes called 'the behavioural ABC' - antecedents, behaviour, consequences *(Illustrate with a flip chart).* The antecedents are the things that trigger or cue or make possible the behaviour; the consequences are the things the behaviour achieves.

*2. Pick two or three behaviours, including one where the antecedent is a facilitating level of help - such as switching on a washing machine, drawing the living-room curtains and folding a sheet with another person - and get staff to volunteer likely antecedents and consequences so that they can be written up under the relevant heading on the flip chart. None of the examples need refer only to people with mental handicaps.*

3. Some consequences are encouraging - either they are intrinsically pleasant, or the behaviour produces the desired effect (the reward is being in control) or they lead on to new activities. Behaviours that produce these kinds of consequence get stronger - they happen more often. Other consequences can be discouraging - something unintended or unpleasant happens, or something that is wanted stops happening. Behaviours that are followed by these consequences get weaker - they happen less often.

*4. Ask staff to volunteer things they experience as encouraging or discouraging consequences, prompting for a range of types of consequence including task completion or achievement, obtaining a rewarding activity or material, social attention and praise, negative reinforcement and punishment. Once praise has been suggested, prompt for the conditions under which people find it rewarding to illustrate the independence of the effect from the stimulus type.*

5. For most people - especially for people who have been deprived of companionship and contact - attention is a powerful encouraging consequence or positive reinforcer.



*6. Discuss common situations where attention is important and ask staff to consider what would happen if it is given or withheld; for example, if no-one paid attention to them when they started to speak. Point out that the attention does not have to be very noticeable or effusive to work as a reinforcer and refer back to the example of praise being sometimes rewarding and sometimes discouraging depending on how it is given.*

7. Attention is often so powerful that it encourages inappropriate behaviour, even if it is disapproving or complaining. This might be especially true for people who have lived in settings where the overall level of attention is very low.

*8. Elicit some examples from staff where (1) inappropriate behaviour is inadvertently attended to and (2) disapproval might still be rewarding. Possible examples might be complaining about feeling tired or ill if it results in (presumably comforting) attention from a spouse or partner or complaining about being kept waiting in a shop, where the reinforcer might be obtaining the attention of the sales assistant even where this is disapproving (of course, another possible reinforcer for this behaviour might be earlier service). Bringing up children is often a rich source of examples but try to include some examples from staff's experience as adults. Arising from examples from child-care, this may be an appropriate point to state the principle that staff will use encouragement for people to join in activities rather than discouragement ('nagging') to stop doing things, and the fixed rule that hitting people is never permitted under any circumstances.*

9. The effect of strengthening particular behaviours by giving them attention works both ways in any relationship.

*10. Illustrate with an example such as the following:*

> *Father comes home tired. The children are being noisy. He sits down and switches on the television and then he can't hear them...Another*

*thing he might have done was shout and threaten to slap the next noise-maker. Often this works for a short time. In this case the children are reinforcing their father for shouting and threatening.*

*In the same way, it is possible that the children have learned that, to gain their father's attention, they must make a noise because otherwise he will just watch the television. The father's attention may actually produce noise-making by his children, even though he thinks his shouting has the opposite effect because in the short-term it makes them quiet.*

11. Because attention is a powerful reinforcer, it is important to learn to give attention in ways that facilitate participation in adaptive behaviour or activities by the people served. This means making sure that the balance of attention is that each person gets more attention when they join in or do appropriate activities than when they are doing nothing or producing inappropriate behaviour. This can be summarised as three guidelines:

11.1 Make sure everyone you are working with has something they can participate in (and preferably a choice of options).

11.2 While people are doing the activity, attend to them briefly at short intervals, sometimes just watching what they are doing, sometimes commenting briefly.

11.3 While people are doing nothing or if they disrupt the activity withhold attention, apart from an occasional prompt to join in again.

*12. Use role-play to illustrate this technique with an activity such as laying a table. Start with a role-played demonstration by the presenters, then with one staff helping one presenter and finally with one staff helping two or three presenters. Use the two handouts (Examples*



*Example 7.3*

**How to facilitate participation**

The aim is to keep the balance of your attention in favour of joining in the activity.

1. Set the occasion: make sure that any equipment or materials needed are set up ready for people to use
2. Invite or remind people to join in: help them get started
3. Interact with each person every few minutes when they are engaged in the activity: comment on what they are doing, talk about the activity, admire their work, pass them more materials or things they need and thank them as they finish the task
4. Try to catch people doing something right: for people who are hesitant or half-hearted or who have inappropriate behaviour that gets in the way of their joining in, keep an eye on them while you are with other people and as soon as they re-start go over and interact with them for a few moments
5. Occasionally prompt people who have given up: try to get them started again without a lot of fuss, or offer an alternative activity if possible.

*Example 7.4*

**Helping each other get it right**

1. Did the member of staff

   - have everything set up ready to start?
   - invite or remind the people they were working with what to do?

2. When people were engaged in the activity, did staff

   - comment approvingly?
   - talk about the activity?
   - admire achievement?
   - provide more materials/equipment?
   - thank people for completion?

3. When people had given up, did staff

   - show interest in the activity of other people?
   - prompt briefly and occasionally?
   - offer an alternative?
   - interact when people started again?

4. Did staff nag or criticise rather than encourage?



*7.3 and 7.4) to structure the discussion and feedback. The person(s) being helped to lay the table should make a reasonable number of errors (so that people can look for 'nagging' versus positive reinforcement) and should sometimes cease to do the task if not contacted for 30 to 60 seconds (so that people can look for organisation versus crisis management). Use the discussion to bring out the importance of being calm and organised as well as the providing the best disposition of attention.*

*How to provide Help*

1. Just as people will be encouraged to join in if the balance of other people's attention favours participation, so they will be more likely to join in if they get the right amount of help. *(Refer back to the original flip-chart to indicate that the session now moves from consequences to antecedents).* Giving help in the best way means making sure that the person is successful, by giving just as much help as they need to accomplish the task, without giving so much help that the person gives up or backs off or lets the task be done for them.

2. There is a general approach which can be used throughout the day in every natural opportunity to help the person join in something new. This can be remembered as MATERIALS-ASK-INSTRUCT-SHOW-GUIDE:

   2.1 First make sure that all the equipment or materials needed are ready for the task or activity. A lot of everyday behaviour can be prompted by finding 'things that need doing', so it is useful to set things up so that the obvious thing to do is to start the activity. *Illustrate by talking about a common activity - such as sticking photographs in an album or using a tumble dryer. Ask staff to imagine they did not know what the next activity was likely to be, to draw out the importance of material cues.*

2.2 If the person does not seem to know what to do, ask them to do the task or tell them where to start.

2.3 If this is not enough help, instruct the person what to do by giving more instruction or gestural prompts through the sequence of steps.

2.4 If the person still seems unsure of what to do, show them how to do it and ask them to have a go.

2.5 If the person is still unable to start the task, guide them through it step-by-step.

*3. Role-play helping someone carry out an activity (such as plugging in and switching on an appliance) and ask staff to identify the different kinds of help used and to pin point the kind of help which was successful. Then role-play with some of the staff to illustrate the different levels of help and how to move smoothly through the hierarchy to offer the effective level. During the role-play, encourage staff to ask their partner to join in and to explain what they want to do before the activity starts (to avoid people being dragged unsuspecting into a new activity) and emphasise the role of staff attention as a probable reinforcer.*

4. There are three reasons why staff should use this hierarchical approach to providing help. It ensures that the person they are helping is successful at each attempt (because they always get enough help to complete the task); it maximises the opportunities for them to practise doing things they have just learned (because the help is never too much too soon); and encouragement is guaranteed because every attempt is successful.

5. Conclude this session by explaining that it is not necessary to go through every condition every time - that this might be too laborious for the person being helped and for the staff - but that what is important is to start with a level of help that is more independent than the person can currently manage with.



*Shaping and Fading*

1. Both reinforcement and help can be used to enable people to develop their expertise and increase their independence. Over a number of opportunities to participate in an activity, the person undertaking the task will make minor variations in how they tackle it: some of these variations will be more useful and some less useful. If the useful variations are noticed and reinforced (by attention, apart from anything else) they will be more likely to happen again. In this way behaviour can be *shaped* by reinforcing successive approximations. The second strategy for increasing independence is gradually to weaken the level of help being provided *(fading)*, but it is important to do this only to an extent that does not threaten the person's successful completion of the task.

*2. Illustrate these approaches by talking about common examples of each in the experience of the staff (such as aspects of learning to drive a car).*

*Introduction to the People to be served and their Families*

The presentation of general approaches to working with people with mental handicaps up to this point has been against the background of little knowledge by the junior care staff of the individuals to be served. This has the advantage that difficulties and objections could not be drawn from individual cases. Once staff have a basic grounding in the way they should view their job, introduction of the people served and their families helps to focus attention on helping real people achieve high aims and overcome difficult obstacles. The format of this session should be a presentation by the staff team leader, who will have visited and got to know the people the staff team will serve.

The content of the session deals with three issues. First, staff are impressed with the need to maintain the privacy and confidentiality of the people served and their families, not only in terms of avoiding gossip and

carelessness but also in terms of letting people leave their past behind. Second, each person's background and circumstances are described, emphasising features of their environment (such as poverty of experience or lack of staff) which have contributed to their current situation rather than non-manipulable issues of unclear importance (clinical diagnosis, speculation about etiology). This session should conclude with a presentation of the individual's major immediate unmet needs, both in terms of important growth areas (strengths) and difficulties to be overcome.

The third section of this session can then lead on to giving precise guidance about how to meet these difficulties when they occur. Difficulties are likely to be of mainly two kinds: behaviour which presents a major challenge to staff (either because it is disruptive or offensive) and serious health care requirements. The goal is not to teach people the theory of the functional analysis of (problem) behaviour or of high-technology medicine: it is to give people clearly identified and agreed effective responses they can make with confidence when the need arises. It also needs to be emphasised that challenging behaviour is expected, is not to be blamed on the person served and can be coped with, managed and in many cases weakened and replaced if staff stick with the person through hard times.

Clearly the nature of these procedures depends on the individual concerned and will have been thought out by the team leader and the project organisers well before the staff training. It is however worth emphasising that strategies to cope with problem behaviour, which are based on extinction of responding by removing reinforcers, can be expected to cause more disruption than procedures which give ready access to the reinforcer through slightly less difficult behaviour or through special arrangements (such as being allowed to strip naked but only in one's room); and that access to a high level of reinforcement at other times is difficult, but essential, to maintain.



*The Use of Job-aids and Reminders to organise Staff Support*

The aim of this session is simply to explain to staff the various job-aids and reminders they will use and how to fill them in. To some extent these will vary depending on how the service is organised, but the description given in subsequent chapters assumes four sorts of record:

1. A *diary* in which staff enter appointments, notes about special arrangements and messages.
2. A book of *duty rotas* so that staff can readily check them.
3. A folder which includes the *daily timetables* discussed in Chapter 8.
4. A folder for each person served by the staff, in which can be kept any individual programmes being used, the participation index described in Chapter 8 and the Personal Priority List or its equivalent from the last individual programme planning meeting.

None of these records or job aids need be kept in a way which is obtrusive or demeaning to the people served. The diary can be kept in a drawer near the telephone; the folders and rotas can be kept in any convenient drawer or cupboard where they can be readily referred to.

**Inservice Training and Induction of New Members of Staff**

Almost as soon as the new service is operational, there will be some staff turnover and the senior staff and project organisers will be faced with the need to provide induction training for one or two new staff. In a rapidly growing service it may be possible to fit these people into the induction programme of other staff teams. At some point, though, it will be necessary to break up the

induction training programme into manageable pieces which can be provided one part at a time to new staff in the first few months of their job. This has the added value that it can provide a refresher course for existing staff and can also include developments introduced after the induction training period.

Probably the key form of inservice training is practice in meeting real challenges, in which the staff team shape up their own performance through the discussion and feedback they give each other in staff meetings and the support and modelling of skilled work they provide. This function of the staff meetings is discussed more in *Chapter 11: Quality Assurance*, but it needs to be recognised from the outset as a major purpose of staff meetings and opportunities for staff to work side-by-side.

**Further Reading**

*Bringing people back home.* Series of training packages produced by South East Thames Regional Health Authority and East Sussex Consultancy and Training Agency. Brighton: ESCATA.

*Caring for people with mental handicap: a learning package for nurses.* (1985) London: English National Board for Nursing, Midwifery and Health Visiting.

Hogg J and Mittler P (1987) *Staff training in mental handicap.* Beckenham: Croom Helm.

Mansell J and Porterfield J (1986) *Staffing and staff training in a residential service.* London: Campaign for People with Mental Handicaps.

Milne D (1986) *Training behaviour therapists: methods, evaluation and implementation with parents, nurses and teachers.* London: Croom Helm.

Ward L (1984) *Planning for people: developing a local service for people with mental handicap. 1. Recruiting and training staff.* London: Kings Fund Centre.

# 8. Planning for the individual

Where they can, most people plan ahead to map out what they are going to do in different areas of their lives. For some things, thinking ahead a few days or a few weeks is all that is needed; but medium-term plans for a few months ahead usually also play a part in everyday life, and in the longer term people develop plans (tentative plans at least) for their work (their career) and their family life.

Of course plans will not always work out and no-one goes through life planning every detail all the time. But planning the future has three things to offer which are often missing in the lives of people dumped in long-stay institutions or on the streets. It enables people to anticipate circumstances and events so they can exercise some choice and control over what happens and what part they play in it. It also provides the mechanism for arranging changes, for the continuing development and enhancement of one's lifestyle. Planning also provides security and stability, so that people are not held at the mercy of every passing circumstance. Whatever mechanisms services use to enable people to plan ahead, these three criteria form the measure of their effectiveness.

Choice should be at the heart of a system of planning for the individual. Many service users have had very limited experience of making choices or of having their preferences attended to and respected. Staff often have little experience of being directed by the people they serve, or of looking for imaginative ways to establish what people's wishes are. But the ability to make informed choices is like other abilities; it can be learned. The task for staff, therefore, is to build a service which offers meaningful choices to individuals, and which respects the choices they make and acts on them, so that people can learn that making choices matters. This does not mean exposing people to hard decisions without any

support: people need to experience mistakes to learn, but the mistakes do not have to be catastrophes.

Individual planning also focuses attention on growth and development, encouraging people to think about where the individual will be at different points in the future. By regularly reviewing all the different areas of activity in which people spend their time, it sets the occasion to look for more adventurous or innovative objectives, and to link together developments in different spheres of the person's life. In this way, all the other activities of the staff supporting a mentally handicapped person - guiding exposure to new opportunities, structuring learning experiences, encouraging social relationships - can derive their goals from a unified appraisal of future directions instead of in a piecemeal or ad-hoc way.

The other side of this attempt to give people's lives some coherent direction is that it protects them from arbitrary change and discontinuity. This too has been a feature of most residential services for people with mental handicaps. Administrative problems have often led to people having to change where they live or what activities they participate in, rather than these changes being planned for the benefit of the person concerned.

The most commonly used method of planning for the individual in mental handicap services is Individual Programme Planning (IPP) (sometimes just called 'individual planning'). Although details differ, all IPP systems involve regular review meetings at which targets are set for the services involved with an individual. Someone (often called a 'keyworker') takes special responsibility for follow-up between meetings and preparing the ground for the next meeting. Individual programme planning started in the United States, originally as a method of spelling out the course of habilitation designed for a person so that service quality could be monitored. Decisions in court cases based on constitutional rights have given people receiving mental handicap services a legal right to individual planning,



whether in the residential setting, at school or in an employment service.

In Britain, individual programme planning has usually been seen not only as a method of spelling out an habilitative programme, but also as a way of coordinating all the services involved with an individual, even where provided by different agencies. It is also seen as making services respond to the individual's views and needs, often by including the service user as a member of the review group.

In the following sections the practical issues of setting up a working system of individual planning are explained, together with some of the problems which arise. The role of the keyworker and the conduct of IPP meetings are described, and examples of the kind of plans made are discussed. Some drawbacks of individual programme planning and possible alternative strategies are suggested. Where practical examples are given these have been drawn from the Jenkins *et al* (1987) version published by the British Institute of Mental Handicap. There are other models of individual programme planning and reference is made to these where they offer a different approach.

## Designing a System of Individual Programme Planning

There are four practical issues to decide in designing a system of individual programme planning: which service agencies to involve, how often to hold review meetings, who should chair the meetings and what sort of people should fulfil the role of keyworkers.

### *Scope of System*

Deciding which agencies should be included usually involves a compromise between wanting to coordinate all relevant services and avoiding lengthy negotiations before starting. It is possible to use individual programme planning entirely within one service, so that the staff supporting people in houses run a system independent of

the day care services or *vice versa*, but this clearly weakens the usefulness of the approach. It means that at least some staff are going to be involved in two sets of meetings about the same individual, or be excluded from contributing to decisions which ought to complement one another. It also means that different priorities may emerge in the different services; and that the consumer may experience uncoordinated, inconsistent and conflicting service delivery.

Involving all relevant services may, however, be impractical. For example, if a person has repeated treatment in a general hospital, is receiving residential care from the health service and attends an adult training centre run by the local authority, it is unlikely that the case-conference system used in the general hospital will be replaced by individual programme planning just for this person.

For the majority of service consumers, it is probably most important to involve the services that support them where they live and where they go during the day, interfacing with other services as best as possible. If individual programme planning is intended for all the consumers in a locality, this means linking the social services day and residential care provision with the education service and in many areas with the health service too. This will involve negotiating with three or four groups of staff who may all have their own methods of review, or who may feel that they do not have the time for systematic planning. The negotiation required to involve everyone may therefore take some skill and some time. Given the difficulty of starting a system without a key agency, an alternative compromise is to start with a few individuals receiving services.

One other point about the scope of individual programme planning is relevant here: the experience of working systems suggests that only those people providing a direct service to the consumer should attend IPP meetings. The traditional practice of including many people in the meeting of high status and marginal relevance to the individual consumer (such as principal



officers of the social services department or schools, or junior medical staff) is wasteful, often hinders the progress of the meeting by distracting attention from the consumer's life to the staff's problems, and can be intimidating to the consumer and their representatives. If strangers attend (for example, if the same set of specialists always attend every review even if they do not know the individual) much of each meeting will be taken up with going over the history of the person's treatment at the hands of services, instead of looking to their future.

### *Frequency of Review*

The special focus of individual programme planning has tended to be the medium term period covering three to six months: this gives a long enough period to encourage people to look beyond the pressures of day to day concerns while being frequent enough to maintain interest. It is also likely that different individuals will need meetings at different frequencies, depending on a whole range of issues including how often the services involved need to check on their own performance to keep on target. Where there is little confidence that services can deliver what the individual needs short intervals will help sustain the programme plan.

Another practical consideration is the balance between the number of service consumers involved and the feasibility of frequent meetings. If an adult training centre has 120 people attending and each person's IPP is reviewed every six months it will need about five meetings a week. This may represent an unacceptable workload to senior staff involved with every individual (and reflects the root problem of services that congregate people in large groups). An alternative to watering down the process by having less frequent IPP reviews is to devolve the review to staff nearer the front-line, so that more people share the workload.

There are, however, two important caveats to this. First, individual programme planning depends on people taking responsibility for achieving goals in the lives of handicapped people, and the involvement of staff nearer the front line will only work if they have the authority to make things happen. So, if senior staff (like the training centre manager or the residential care team leader) want to give away the workload, they must also give away some of the authority. The second obstacle to running a sufficiently frequent system of IPP meetings for a large group of consumers is that some essential attenders may be the same for many people. In the example already given, a social services area office may have allocated a single social worker to all the people who attend an adult training centre; although this person is unlikely to be directly involved with everyone at the same time they may still have difficulty attending the required number of meetings.

Dates for meetings should be planned so that they become a regular commitment for the people mainly involved. This removes a great deal of extra, unnecessary work in trying to fix meetings on an ad hoc basis.

### *Chairing Meetings*

The IPP system is designed to balance objectives and competing priorities in all aspects of the service user's life. The person chosen to chair IPP meetings will be instrumental in ensuring that this balance is achieved and should therefore not be someone unduly influenced by their own involvement in the person's service network. This means that the chair should preferably not be taken by someone managing part of the service (like a residential staff team leader). Staff in this sort of position are likely to be too pressured by the day-to-day constraints of their job to take a broad enough view. They are also likely to be important contributors to decision-making in the review and will not therefore be able to manage the task of chairing the meeting and



recording its decisions at the same time. It is useful to have a chairperson who knows the service user and the staff and services involved with them. These requirements may often be met by social workers, community nurses or psychologists who can take the chair in a number of (or perhaps all) IPP meetings in a local area. Where the workload in an area is shared, it is essential to maintain the same chairperson for each individual's reviews.

Whoever is chosen, the person who chairs an IPP meeting needs to provide enough leadership and structure to ensure that an agreed list of positive objectives is extracted from the range of individual needs in a reasonable time. This implies a number of skills. The chairperson needs to be able to help group members re-state problems or needs as positive objectives, taking often rather vague or general statements of need and helping the group focus on one or a few specific, tangible goals. The chairperson must also help sort out priorities where there are many possible goals, and an ability to keep coherent notes of priority areas selected is essential.

As well as skills of running the IPP meeting itself, there are some coordinating, administrative tasks best done by the chairperson. These include checking that keyworkers are up to date in their preparation for IPP meetings and the analysis of any summary IPP information used in monitoring or quality assurance.

### *Choosing Keyworkers*

The keyworker in an IPP system has the job of contacting everyone working with a service user before the IPP meeting to elicit their ideas of the person's needs. At the meeting, the keyworker can help them introduce their contribution and participates in the discussion, often paying special attention to supporting contributions by the person served or their relatives. After the meeting, it is the keyworker's responsibility to check on achievement of each goal.

Usually, the keyworker task is taken on by a member of staff who knows the individual handicapped person and works with them in their home or during the day. Being a keyworker can be a useful form of role development for front-line staff, although it is important that staff get the support they need until they are confident about the job.'Senior staff need to provide time and the use of a desk and a telephone for keyworkers to contact everyone involved with the individual they serve and, together with the person who chairs the IPP meeting, they may need to encourage and help the keyworker relate to people of different status and professional identities.

**Preparation for the IPP Meeting**

Preparation for an IPP meeting consists of identifying the people who will form the review team, interviewing them to get their ideas of the individual's current needs and collating these views in a form which can be used in the meeting.

This is conveniently done using a Personal Needs List like that shown in Example 8.1 on page 187. This is a single sheet of paper listing all the areas in which the individual person might have identifiable needs and the names of the relevant staff who will form the IPP team at that meeting. The keyworker should start collecting information on the needs list about three or four weeks before the meeting.

*Identifying the IPP Team*

The first issue in identifying the planning team is to decide how to involve the service user in the individual programme planning process.

One approach (used for example by Blunden) is to include the service user in the meeting no matter how handicapped. The rationale for this approach is that it ensures that if the person can make any contribution at



all, they are there to do so; and that their presence will help ensure that the client's interests are the main focus of concern at the meeting. The criticism of this approach is that it can become tokenism, doing nothing to make the planning team think differently about their commitment to the individual and providing a boring or perhaps even oppressive experience for the service user; it can also divide staff and divert energy from embarking on the new planning process. The alternative is inclusion only if the preparation and meeting will be structured so that the person can play an active part, at least to some extent.

In reaching a decision about this issue there are a number of useful ground rules. First, the decision should not be a blanket decision about everyone in the IPP system; each individual is different and the extent and method of their involvement will vary. Nor should it be a decision made for all time; people change, and with help will usually grow to exercise more choice once they are given the opportunity. There will also be growth in the planning team members' commitment to the process and their ability to involve the handicapped individual. Finally, it should not be a decision about whether to involve people, but about how to involve them, finding ways in which people can be introduced to aspects of both the preparation and the meetings.

One way of trying to enable a person with profound handicaps to influence the IPP process is for the members of the planning team to undertake some special work with the service user when the system first starts, so that they all gain a detailed knowledge of the person's life history, experiences, character and preferences as well as their abilities and disabilities. Apart from increasing team members' understanding, this might also show ways of including a profoundly handicapped person in individual programme planning. A good example of this method is the *Getting to know you* handbook by Brost *et al.* While working on methods of involving people effectively in the IPP process it is also important to include someone who can take the role of an independent advocate to speak for

the person's interests (if necessary, against the interests of staff or family or management).

Once the system is working, the routine first step is to check the list of staff who will make up the planning team. Against each title on the list enter the name of the person concerned, adding people who are involved with the individual as necessary. As a general rule, some people should always be included either because they have a right or because they have formal responsibilities for planning for individual service users. People in this category include the service user, their relative or advocate, their social worker, the person who is responsible for managing the residential service for which the user is eligible (even if they have not yet left their family home) and the person who manages their day service (whether school, assisted employment or day care). Apart from professionals who should be formally involved at each meeting, the list is amended to include only those people who are currently involved with the service user. In practice, then, most planning teams comprise a core group of people with some extra staff who change as the person's use of services changes.

### *Interviewing Members of the IPP Team*

Having identified the individuals who will form the IPP team for the next meeting, the keyworker contacts each person to add their perception of individual needs to the needs list. These contacts can be by telephone, but for the first meeting attended by a particular professional (or the keyworker), or if a member prefers, a short face-to-face discussion may be more appropriate. Obviously the keyworker may need to spend more time than this with the service user to elicit their views.

For each person, the keyworker goes through the needs list prompting for particular issues the team member wants to raise. When working through the needs list, the keyworker should note down needs identified concisely and clearly - short notes rather than paragraphs of text



are required. It does not matter if some needs are stated rather vaguely, since one of the functions of the IPP meeting is to turn them into clear goals. As the keyworker moves from one planning team member to another, it helps to show each person the needs list with everyone else's views, to spark off new ideas if someone is uncertain. The keyworker should also add their own views, since they already know the handicapped person and will have something to contribute.

At the end of each meeting with a planning team member, the keyworker should ask whether there is anyone else working with the service user. This provides a check that the list of members of the IPP meeting is accurate. Finally, this interview provides an opportunity to remind the team member of the date, time and venue of the meeting. If meetings have been scheduled as a regular commitment, this should be enough of a reminder, so there is no need to send out written notice of the meeting.

When the keyworker has collated the views of all the members of the IPP team, they need to photocopy enough copies of the Personal Needs List to hand out at the meeting. This then forms the agenda to help generate the Personal Priorities List: it also constitutes an important record of the service user's needs constructed jointly by workers from different professions and different agencies.

### *Completing the Personal Needs List*

Example 8.1 shows the Personal Needs List. The first page includes a list of the members of the IPP team and deals with the major day or residential services which might be available to the individual. The keyworker should ask about the strengths and weaknesses of current placements and possible future needs for accommodation (holiday, short-stay or permanent alternatives), education, employment or employment substitutes. This part also includes the financial status of the person, so the keyworker should check whether there are money

## *Example 8.1* **Illustration of Personal Needs List**

INDIVIDUAL PROGRAMME PLANNING — NEEDS LIST

Client's name Tom Briggs..... Key worker Mike Fielding...

IPP meeting to be held on ....11/7/86..... (date) .10.00..... (time)

at .Social Education Centre..... (place)

PROGRAMME PLANNING TEAM

The keyworker should establish which people on the following list have been in contact with the client since the last IPP meeting. Each of these people should be asked what they would like to put on the Needs List as priority areas for work, and invited to the meeting.

- ✓ Client Tom Briggs
- ✓ Family/~~advocate~~ Mr and Mrs Briggs
- ✓ Residential care person-in-charge Mary Mckie
- ✓ Manager/~~employer~~ Mr Thomson
- Special Care Unit Manager
- Head teacher/class teacher
- Psychologist
- Community Nurse
- Social Worker
- General Practitioner
- Psychiatrist/other medical specialist
- Speech Therapist
- Physiotherapist
- Occupational Therapist
- Other

1. PREDICTED REQUIREMENTS AND NEED FOR MAJOR SERVICES

Long term accommodation

Short term care

Day care/training Increase times of attendance (now 10-3p.m, 2 days a week) or find alternative.

Education

Work

Finance



### Personal Needs List (cont.)

2. TEACHING OR LEARNING PRIORITIES: Skills to acquire in the next 9 months.

Self care — Complete dressing skills (now can't do fastenings)

Domestic — Load dishwasher, washing machine

Daily living ) Community living)

Communication — Use clear signs especially for help and for toilet.

Behaviour problems — Needs to stick at the task (now wanders and pesters other people)

Close personal relations

Use of leisure

Physical development

Needed in the next nine months concerning the areas of:-

3. Health/Hygiene — Reduction in drugs (now half asleep most afternoons)

4. Physical appearance & co-ordination — Decent haircut.

5. Social relationships/ companionship — Increase visiting of family in their home.

6. Opportunities for increased or different occupation:

Household — More variety of tasks

Day care/work — Needs more interesting tasks.

Leisure

Community events — Going to Cinema.

problems and whether the person appears to be claiming everything to which they are entitled.

The second page of the needs list asks people to consider what individual skill development is needed in the next planning period. Alternative breakdowns of skill development could be just as useful since the aim is to spark discussion rather than constrain the way team members think about the issue. There is no pressure to identify a need in each area - an individual may have specific needs in only one or a few teaching areas. The remainder of the needs list relates to other aspects of life, including health and appearance, social relationships and friendship, opportunities for more or different kinds of involvement in activities and participation in community events. The extra weight given in the example to teaching needs reflects the emphasis that services have given to teaching people with mental handicaps as a major task.

Some individual programme planning systems, such as that described by Blunden, leave out the extra goal areas under the skill development heading; the handbooks produced by Houts and Scott emphasise teaching rather more. It would certainly be possible to expand the other areas to equal importance - by, for example, looking at needs on a grid (Example 8.2) listing different areas of a person's life (self-care, household management, work, education, leisure etc.) by personal resources (skills, health, appearance, involvement or experience and relationships). The other common modification to this part of the process is to include on the Personal Needs List a section for 'strengths'. The idea is that the things the person likes doing or can already do should influence the choice of goals, although sometimes this is broadened to include opportunities such as someone willing to undertake a special commitment to the individual (strictly, strengths in the service network rather than in the individual).



*Example 8.2*

**Alternative Format for Identifying Personal Needs in Individual Programme Planning**

| | Personal care | Household management | Work | Education | Leisure |
|---|---|---|---|---|---|
| Choice | | more variety of tasks. | | | |
| Skills | dressing (fastenings) | | | use clear signs for 'help' and 'toilet' | |
| Appearance/Health | Decent haircut | Reduce drugs | | | |
| Experience | | | Needs more interesting tasks. | | going to cinema. |
| Relationships | | | Needs more encouragement to stick at task. | | Visit family more. |

**Holding the Meeting**

The first individual programme planning meeting involves working through the needs list, identifying feasible goal areas and specifying clear goals for the Personal Priorities List. Subsequent meetings include these steps but also require the planning team to review the progress of goals set on the last Personal Priorities List before starting to construct the new one.

Within the meeting, the keyworker has two roles. They should clarify points which are not clear from the needs list, if necessary by describing the discussion they had with team members; and they should participate fully as a member of the planning team who knows the service user well and is therefore well placed to comment on priorities in their life. In fulfilling both these roles they can also act to support contributions by the handicapped person and their relatives.

Apart from steering the meeting through the task of compiling a Personal Priorities List, the chairperson needs to pay special attention to facilitating working as a team. It is important that everyone, no matter what their position, feels their contribution is valued, and that high-status professionals avoid dominating the discussion. Because everyone has experience of other models of review meeting (like case conferences) it is important that the chairperson preserves the intended quality of individual programme planning meetings. This means, among other things, attending to the following issues:

1. focusing on the achievement of goals rather than discussing why things go wrong
2. making a genuine attempt to involve the service user as much as possible and discussing issues as if the person understands so that they remain the focus of attention
3. a veto on talking about the person as if they were not there



4. the inclusion only of people with a direct commitment to serving the person, to avoid the meeting degenerating into another meeting to resolve the professional or service problems of staff.

*Constructing the Personal Priorities List (Example 8.3)*

At the start of the meeting, the chairperson should make sure everyone has been introduced and explain that the purpose of the meeting is to work through the needs list and decide, for each of the needs identified, appropriate objectives which will form the individual programme plan until the next meeting. They should check that everyone has a copy of the needs list and explain that they will keep a record of the issues discussed, the goals specified and who takes on responsibility for making progress towards each goal.

The issues identified in the Personal Needs List should each be discussed by the team. Different members of the team will often have views about an issue even if only one person originally suggested it and this discussion can help clarify the objective. It is important in this discussion to make sure everyone's views are represented, so that the objectives emerge from a consensus. Hidden reservations will cause problems later, especially if the member concerned will be called upon to help achieve an objective they are less than entirely happy with.

It will help to keep the discussion firmly focused on the objectives the team is trying to set. Most people readily slip into speculating about why things are as they are, or explaining how difficult their job is. These things are often interesting topics in which everyone can join without taking on any extra work; they do however take a lot of time and do not usually contribute much to setting objectives. It should be possible to contain the whole IPP meeting for an individual to about an hour.

As each objective emerges from the discussion, the chairperson should ensure that it is phrased clearly and that all members of the planning team agree with it, and

*Example 8.3*

**Individual Programme Planning: Personal Priority List**

Individual: Tom Briggs Date of meeting: 11.7.86

People present at meeting:

Tom Briggs, Mr & Mrs Briggs, Mary McKie, Mike Fielding, Mr. Thomson

| Area | Discussion | Objective | Person responsible | Outcome |
|---|---|---|---|---|
| Day Care | Tom leaves at 3p.m on the first bus because sleepy (reduce drugs) | Tom will leave on last bus at 3.55p.m. | Mr. Thomson | |
| Self care | Tom can now put most things on if given in the right order + with help for final adjustments. | Tom will learn to fasten coat or jacket buttons. | Mary McKie | |
| Domestic | Loading dishwasher causes some problems because Tom has trouble finding the slots. | Tom will get some practise loading and unloading the washing machine | Mary McKie. | |



should then write it on the Personal Priorities List (Example 8.3). In this example, the format requires that the chairperson enters the area of need concerned in the first column, the main points of the discussion in the second column, the objective in the third column and the person who will be responsible for achieving it in the fourth column. It is important that the person taking responsibility is present; if achieving a goal requires involving someone not present the priority written on the list should be in the form of a referral, with someone present volunteering to make it.

It is not necessary to set an objective for each need on the list. Some service users may have many more needs than can be tackled before the next meeting and it will be appropriate to select the highest priorities areas to start with.

The Personal Priorities List is complete when the individual programme planning team has worked through all the issues raised on the Personal Needs List in this way. At the end of the meeting the chairperson should undertake to circulate everyone with a photocopy of the Personal Priorities List, asking that people respond quickly if they feel that the discussion or an objective is misrepresented. It also makes sense to remind people of the date of the next meeting before they leave.

When copying the Personal Priorities List for circulation, it is important not to spend time re-writing and editing the notes taken in the meeting. The List is not intended to be minutes of discussion and does not need to be typed or specially prepared. It is a working document, an aide-memoire, and it is important not to create more paperwork than is needed. The objective should be for the chairperson to take brief, clear notes in the meeting rather than spend time on them afterwards.

*Subsequent Meetings*

Further meetings of the IPP team are conducted in the same way as the first one except for the first step in the meeting.

This first step is to go through the Personal Priorities List set at the previous meeting and ask for a report on each objective from the person named as responsible for it. The report need only be brief, saying when the person began work on it and what progress they have made. The keyworker will have checked this out informally before the meeting and the chairperson should enter the information on the Personal Priorities List. It is important that an entry is made for each objective: individual programme planning is not just about setting goals but about making progress towards achieving them and rendering the service accountable for its adequacy.

Once a report has been made on each objective set last time, the meeting can continue by reviewing the new Personal Needs List. If people have had problems working on a goal it is important not to spend much time listening to explanations of why progress has been so slow. There is limited time and the IPP meeting is not the right place to sort out a team member's problems. Unmet needs will in any case remain on the current agenda to be discussed in the second part of the meeting, where they can be addressed using the constructive approach described above.

**Follow-up after the Meeting**

Once members of the planning team have received their copies of the Personal Priorities List after the meeting they should begin to tackle the objectives for which they accepted responsibility. Some individual planning systems include a check half-way through the period between IPP meetings to see whether each person has started on their objectives. The argument for doing this is that it acts as a reminder to busy people and it



allows the chairperson to intervene if extra help is needed. Otherwise it will not be until the keyworker makes contact three or four weeks before the next meeting that lack of progress will be discovered.

Another issue that will arise between meetings of the IPP team is the need to take on new objectives not foreseen at the last meeting, or to extend or adapt an existing objective. It is important that members of the planning team do this when it is needed and do not wait slavishly for the next meeting. The mechanics of individual programme planning are there to help make better plans, not to slow down the process or hinder people's creativity.

**Putting a System into Practice**

There are three main approaches to designing a staffed housing service around individual people's needs. Where individual programme planning already exists or people are ready to set it up, it can be used as the basis for planning re-housing. If this is not possible, then it may be possible to set up a limited form of individual programme planning for a few people who are then re-housed, as a pilot scheme which shows how housing provision can be related to individual needs. If neither of these are practical (where, for example, people have to move quickly because of hospital closure or where it is important to rescue them from continued exposure to a poor-quality environment), then alternative ways of matching provision to individuals need to be discussed. In this case the implementation of a system of planning for the individual will be one of the early priorities in the developing service.

The major risk of any attempt to organise the delivery of care is that people can learn to go through the method mechanistically, filling in the forms, attending the meetings and using the jargon, but setting goals that make no sense, are trivial or are rarely achieved. It is therefore important to start by training the people who are going to

participate so that they expect something new and different. 'Training' in this context need not mean the initiator telling everyone else what a good idea individual planning is and how it will be done: talking through the issues may be a lot more effective. The design of the forms or any other administrative details are less important (partly because there are plenty of examples to follow and they are easy to change) than talking through what people think an individual planning system should do for the people served.

This kind of preparation sets the scene for focusing in the beginning on effectiveness rather than comprehensiveness. It makes sense to start with a relatively small group of service users and build up numbers only as the system proves its worth. In doing so, however, it remains important to consider the eventual organisation of the scheme; involving all the parties needed even if on a pilot basis rather than starting in one agency or facility in isolation from others.

### *Effectiveness in selecting Goals*

The most basic requirement of IPP objectives is that they should be specified clearly. This means that the content of each objective should not be ambiguous, that it can be seen to have been achieved and that the person responsible for achieving it is named.

There are usually so many desirable objectives that the planning team has to select those to be worked on between one meeting and the next. The major guide to choosing between objectives should be the three criteria given in the introduction to this chapter; to what extent does an objective reflect a real choice by the individual, enhance or develop their lifestyle and provide security and stability in it. To these three, a fourth can be added: to what extent is an objective feasible?

Finding ways of presenting people with meaningful choices, especially if they are severely handicapped, will tax the ingenuity of staff and a realistic acceptance of



what staff can and cannot offer is probably more sensible than token acknowledgement of the issue. But the evidence suggests that whenever people in mental handicap services have been given the opportunity to make choices they have taken it and that people thought to be too handicapped to express a view can learn to do so given the right conditions. This cautions against a ready dismissal of anyone's ability to decide for themselves.

A major challenge for the IPP team is therefore the extent to which the objectives they are selecting represent real choices by the individual being served. As well as offering choices in the meeting, either by explanation or by using pictures or sample objects, there may be a role for people between meetings to open up new experiences for the person, so that they can sample different experiences and activities, to help gauge what they prefer.

A similarly self-critical view is needed in relation to the impact on the lifestyle of the individual. Many objectives set for service users really reflect the service's priorities more than they do the person's. Which has more impact - learning to do up buttons or eating out twice a week? Impact may be measured in terms of the 'five accomplishments' described in Chapter 1 so that goals for opening up new opportunities, by enhancing the skill level or breadth of experience the person has, are complemented by goals about the experience of making decisions, or goals about how the individual is seen by others. Such objectives help break down traditional stereotypes of what people with mental handicaps are like and what they can do. Objectives can also be chosen for their impact in avoiding bad outcomes. If the person is at risk of being excluded or rejected from an important activity or source of experience, objectives that make this less likely will have greater weight.

Feasibility should not be the main criterion because one of the products of individual programme planning should be a tension drawing services to respond more fully to individual needs. Blunden suggests that when an IPP team identifies an objective that cannot be met from

the services available, they should send a 'service deficiency report' to the manager responsible. It is however important to set goals that are not unrealistic in terms of what the planning team members can achieve. If there are objectives which need more staff, more resources, more skill or more commitment than can be obtained at the present, then it may be possible to set more limited goals that build towards achieving these conditions.

*Effectiveness in running the System*

As well as the issues discussed earlier in the chapter, there are three practical steps that may help make an individual programme planning system a success. The first is that, at the outset, the members of staff who participate in planning teams can spell out the resources and services each can offer through the IPP system. This makes explicit the kinds of assistance team members can access, although it helps to be cautious about constructing a 'shopping list' since team members may often be called upon to try for extra resources or to use them in new ways.

Second, as part of this preliminary work, it is important to ensure that other competing systems of case-conferences or individual planning are supplanted. No system can work effectively if there is another group of people, somewhere else in the organisation, who think they control decision about planning for a particular person.

The third point is that IPP team members need to see that people notice the difference between just going through the motions of running the system and actually using it creatively to enhance people's lives. If there seems to be no difference (because the system becomes rooted in trivia), initial enthusiasm will be lost and the process will become routine paperwork. Similarly, members of the planning team need to question whether they are making major changes for the individual person



outside of the IPP system, risking conflict, muddle and insecurity and detracting from the perception of individual programme planning as a worthwhile exercise.

*Developing the System*

Individual programme planning is not an essential part of a good service. To use the idea of the 'culturally valued analogue' from the normalisation literature, a person who could probably would not choose to take part in six-monthly meetings to negotiate what they want from a group of disorganised professionals - they would want to decide for themselves and tell others what they wanted. They would expect service personnel to be well-organised enough to coordinate themselves. Some housing services are already beginning to meet such demands from people who have left mental handicap hospitals.

Another area where existing IPP models are rather weak is that they focus only on the three to six month timeframe, while some of the most important plans people ideally make are for the much longer term - planning a career, building their family life and so on. The ease with which these issues can be avoided just shows how little future most handicapped people in residential care have; mostly, they will remain poor, living in the same place, doing the same thing during the day, for most of their adult life. Some recent approaches to individual programme planning attempt to begin to address this need.

This means that existing models of individual programme planning are no more that a start in meeting the needs of the people served. What is likely to happen is that models become more diverse as some people make demands on services directly or with help from advocates, while others participate in a variety of discussions about their future. As services become more coordinated there will be less of a need to use IPP meetings to negotiate between agencies, and a clearer attempt may be made to relate medium-term objectives to long-range life goals.

**Further Reading**

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Jenkins J, Felce D, Toogood S, Mansell J and de Kock U (1987) *Individual programme planning.* Kidderminster: British Institute of Mental Handicap.

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# 9. Enabling individual participation

"Inactivity withers the body, and the mind". The fundamental issue in the staffed housing model of care is how to organise the residential environment so that it promotes rather than hinders effective participation in everyday household activity by the people served: i.e. people who have severe and profound mental handicaps.

Traditionally, residential environments have been organised to deny this opportunity to people with severe and profound mental handicaps. The organisational and staffing arrangements take away all opportunities to participate in the range of daily living activities that ordinarily occupy the householder, leaving people with enforced leisure as their major source of experience. Sometimes (rarely) sporadic individual teaching programme sessions are overlaid on this pattern. The staffed housing model provides the opportunity to overturn this pattern and to aim for participation in household activities as a major service goal.

There are three aspects of this issue which need to be clearly understood: why participation is the primary goal rather than teaching; why the use of household activities is better than recreational or educational activities; and why structured participation is better than 'free choice' or inactivity.

Teaching is an important part of the service for people whose primary disability is in learning. Given a choice between always being helped to do something or being able to do it independently, most people would choose the latter because of the increased freedom it brings (freedom from needing other people, freedom to choose when and how to do it). For the service, teaching is more efficient than helping because it frees staff time which can be redirected to other areas of need.

However, our ability to teach in a formal, direct sense is severely limited. Although an enormous contribution has been made by behavioural psychology to

understanding effective teaching, there is not yet the knowledge base, let alone the disseminated skill, to teach more than the most basic range of living skills to people whose learning disabilities are substantial or complicated. If teaching is identified as the primary goal, the people served are necessarily going to spend most of their time learning rather than doing - travelling on the journey rather than arriving at the destination. And then one might ask the question "why teach at all if not to facilitate participation"?

An exclusive focus on teaching also tends to create an artificial distinction between being "in a teaching programme" and being "out of programme". This can lead to all the effort going into "programmes" which are of limited duration to the exclusion of what happens during the rest of the day when people are left largely to their own devices. In practice, people may spend most of their time with little or nothing to do, except for the occasional teaching session.

This is, of course, a parody of effective teaching. Specific teaching interventions work best when grounded in a wide range of experience of related tasks, so that the selection of goals is derived from important challenges in the person's experience (increasing motivation), there are many opportunities to practise component or precursor or emerging skills (consolidating learning) and there is most opportunity for incidental learning in response to natural contingencies (helping acquisition in the target skill area and improving the chances of generalisation).

Therefore, although teaching is an important service objective, it does not supplant the provision of opportunities for the people served to participate in a wide range of relevant activities, as an important service goal. Given the relative weakness of teaching skill, such participation may itself be more responsible for progress in learning than formal teaching programmes.

Where the importance of participation in activity is recognised, many services set up opportunities for the people served to use recreational or leisure materials designed for young children. This arrangement is based



on the belief that such activities should be chosen either because they are simple enough for very handicapped people to do, or because they are thought to be intrinsically rewarding. Housework, on the other hand, is seen as mere drudgery, with echoes of the exploitation of patients as cheap labour in long-stay hospitals.

These arguments do not stand up to examination. Suggesting that the kind of toys available in most residential settings are the materials of choice because they are simple to use confuses simplicity with childishness. There are many activities or parts of activities in adult life which are simple; and many toys require a level of symbolic competence not possessed by people with severe or profound degrees of mental handicap. While collecting many hours of observational data in research studies, we have been struck not by the eagerness with which people approach recreational materials but rather by their lack of interest.

There are further arguments against using recreation as the principal activity. First, it is difficult to provide as much variety as anyone might need, whether or not they had shortened attention span and limited skills. If a person can already do the task (i.e. it is within their existing repertoire and they are not being taught) then it is often completed quickly and even a large stock of materials cannot prevent the same activities being presented to the individual again and again in the course of the day or week.

Secondly, far from being more interesting than ordinary activities, an exclusive focus on recreation seems to pose a number of problems of motivation. It is open to the influence of social pressures (either directly experienced by users or mediated by staff perceptions of the worth of the activity and the effort it merits) that it is trivial, time-filling and meaningless. Does it matter how fast people complete jigsaws or stack blocks? It may also be that recreational activities, since they are not linked into the sequence of essential daily activities, depend more on extrinsic social reinforcers than on

intrinsic sources such as achievement, control and completion.

In the residential situation, the age-appropriate sources of activity involve those housekeeping tasks which the lives of the service users generate: the need to shop, prepare food, cook, lay the table, wash up, tidy, clean, launder, decorate and garden. Instead of doing all the housework as efficiently as possible and then attempting to occupy people for long periods of each day with toys, staff can be organised to spend most of the day doing housework with the people served, arranging each activity to maximise the opportunities for people with different levels of ability to participate and control the action. Such activities would be age-appropriate for adults and, even for the most handicapped people, may not have the negative connotations attached to child-like activities.

The third issue to be dealt with is what balance to strike between organising the environment to promote participation in activity and allowing people to do what they choose, even if this is nothing. 'Choice' is a loosely used term in this context: better to distinguish between different conditions of choosing. We say that someone chooses to do one activity rather than another when they can do both (they have the skills, resources and time and they control access to each option). We can also say that someone who is fat 'chooses' to eat more than they need, but we recognise that for many people the availability of attractive food makes it harder for them to choose not to eat.

For people who have difficulty expressing their preferences, whose range of experience is limited, and whose ability to control their environment is severely impaired, failure to create opportunities for participation is just as 'controlling' as setting up only one option. It ensures that people can only do nothing. The goal should therefore be to find ways of enabling people to express their preferences, to ensure that they routinely experience a wide range of different circumstances and to arrange their environment so they can control it. Only as these



conditions are fulfilled can one say that people are in some sense making informed choices.

The remainder of this chapter addresses these issues in four parts. The next section deals with how to arrange activities so that they invite participation, paying particular attention to arranging the equipment and materials involved so that they convey as much as possible what needs to be done. This leads on to the role of staff in helping people join in activity and in maintaining their enthusiasm. The third section of the chapter stands back from this 'micro' level of organisation to examine the rhythm and variety of everyday life in the home and the role of staff in establishing a good mix of activities. This section also deals with choice, variety and the exercise of control by the people served. Finally, the chapter addresses more intensive ways of extending individual experience, in terms of teaching new skills to open up new areas of opportunity, designing the environment to support independent action by people with major physical handicaps and dealing with behaviour that is likely to limit or deny a person's access to important situations or activities.

## Starting with Opportunities

The starting-point for enabling individual participation is the organisation of each task or job so that people can readily join in. There are two ways of doing this: either an individual can tackle the whole job (such as vacuum cleaning a carpet, laying a table or burning garden rubbish), in which case the role of staff is to provide whatever level of help the person needs at each stage of the task; or the task itself can be split up into those parts the person can do alone and those that staff or other people can do. Both methods need to be used, but the first approach requires one-to-one staff availability and, where one staff is helping two or three people, splitting up the activity into components that people can complete independently is more likely to be useful.

Breaking down each task into its constituent components is, of course, part of the process of task analysis used in precision-teaching methods. It is however important to note that here it is being used not to teach - which would require one-to-one staffing - but to identify parts of activities that people can already do to an acceptable criterion. Thus, for example, in laying a table for dinner one person may be able to place the items on the table but not to find them or arrange them correctly; these tasks may be done by other people or (if necessary) by staff. Even if one person can do the whole thing, it may still be worth sharing out the components so that everyone has something they can do.

The role of staff in this situation is to facilitate by thinking through the nature of each activity, getting things ready and watching for snags or gaps where they can help. Sometimes they may need to provide some help throughout a particular stage (eg. slicing a roast joint of meat) but they will usually only do part of the task on their own where it is a short difficult step between two parts that can be done by the people served. For example, changing the blade of a food processor between preparing different foods is quick and difficult - if staff do it the people doing the food preparation can get on with the things they can do with minimal fuss and interruption.

People with profound mental handicap or with major additional physical handicaps are often most at risk from being excluded from activity because staff find it very hard to conceptualise activities in a way that they can be tackled relatively independently by these individuals. Thus, these people experience the vicious circle of low expectations and low achievement described in Chapter 1. Analysing complex tasks does however offer a fruitful approach to finding opportunities for these people. Tasks like dusting a polished surface, carrying equipment to where it is needed, holding down the switch on an electric coffee grinder, pushing laundry into or pulling it out of a washing machine are all as accessible as fumbling with babies' rattles and cot mobiles. Once the pressure to do housework quickly (to make time for the cot mobiles) is relieved, then it is easier for people to participate at their own pace.



Particular attention should be paid to setting up the equipment and materials needed for each activity. Materials themselves can convey a lot of information about what the next step is and how to do it; setting the situation up for people who have difficulty identifying these things can be extremely helpful. It also has the advantage that people associate the activity with the situation rather than learning to respond to verbal permissions or cues from staff, so limiting their dependence on staff presence and helping people make the natural relationships between items in chains of behaviour.

In practical terms this implies that staff are always one step ahead of the individual or individuals they are helping. They not only had all the equipment together when they started the activity, but they also had it set out in the most helpful way so that people could get going as soon as they arrived and, while one step was underway, staff got the next step ready. This level of preparation is almost unknown in many services and to achieve it has implications for scheduling activities and deploying staff, issues dealt with below.

## Structuring Staff Helpfulness

Finding the parts of an activity a person can do on their own still leaves many situations where, in order to do the task, people need help; and in all activities, people will need encouragement to join in. How staff deliver help and encouragement has implications for the ease with which people engage in activities and their motivation to do so.

In terms of providing *antecedent* help, the goal for staff is to make sure that the person is successful, by giving just as much help as they need to accomplish the task, but without giving so much help that the person gives up or backs off or lets the task be done for them. In

this way the handicapped person is maintained at the threshold of confident competence, where they experience most success under the conditions of greatest challenge.

The first 'level' of help of which staff should be aware is simple presentation of materials in the way already described. Having said what the task is or what to do next by way of general explanation and courtesy (eg "the washing up needs doing - will you help?"), and having got to the prepared situation (eg the kitchen sink) staff should hold back for a moment to see whether the demands of the situation itself are enough to elicit the involvement of the person concerned. If they are not, then it is appropriate for staff to work up the hierarchy of levels of assistance until they find the lowest level which guarantees successful execution of the task.

This hierarchy can be summarised in the phrase 'ask-instruct-show-guide'. If the person does not seem to know what to do, staff should ask them to do the task or tell them where to start. This level of help will be useful where the person concerned knows what to do but not quite when to do it; an alternative to spoken help may be simply to point at the task or at where the person should begin.

If the person still seems unsure of what to do, staff can instruct the person what to do, either by way of explanation (if the person understands spoken explanations) or by extra cues and prompts (such as pointing to each step in turn as the person completes the previous one or taking away some of the clutter of materials in front of them). Since the aim is to provide extra help to enable the person to do the task successfully, brief and clear instructions or prompts are likely to be more useful than if they are buried in streams of conversation.

Where this level of help is insufficient, staff can show the person what to do, either by demonstrating the task first or by doing it alongside the individual so they can imitate each step. Many activities lend themselves to this kind of side-by-side approach in which staff model the task.



Finally, staff can guide the individual through the difficult step or the whole activity. The form of guidance itself can vary from minimal help with positioning through to complete guidance in which the individual has no possibility of error.

Although easy to remember and useful in staff training, the ask-instruct-show-guide hierarchy is of course a clumsy representation of the skill staff need to develop. With practice, staff should be able to integrate varying levels of help into the flow of their interaction with the people served so that the shift between levels is imperceptible. Although this will look 'natural' and unplanned to others, it is of course essential that staff remain aware of the amount of help they are providing as against what the person needs to do the task.

Nor is it necessary to toil laboriously through every level of help before getting to the one which is effective: as staff get to know the people they serve, they will be able to identify the critical range of help for different tasks for each person. It remains important, however, to start with a little less help that the person currently needs so that they are always given the opportunity to extend their independence. In this way staff are always setting up opportunities for learning and, over time, they can fade the level of assistance in response to increasing independence and greater ability to take control by the person concerned.

The other major aspect of staff helpfulness is in their responses to individual behaviour in mediating the *consequences* of the person's actions. According to the behavioural paradigm, some consequences will increase or decrease the probability of the particular behaviour occurring again. Which consequences have these effects is an empirical issue and can be expected to vary with individuals and situations, so that a simple assumption that 'nice' things are generally likely to increase the probability of behaviour they follow will be wrong in certain circumstances.

For many people with severe and profound mental handicaps, however, it does appear that simple attention

from other people does have this positively reinforcing effect. This is perhaps not surprising given the deprivation of contact experienced in many types of setting. Therefore, as a basic minimum standard of performance, staff must be able to deploy their attention (irrespective of whether approving or disapproving) contingently and differentially in favour of participation in appropriate activity.

This means making sure that that each person gets more attention when they join in or do appropriate activities than when they are doing nothing or producing inappropriate behaviour. This can be summarised in the three guidelines used in the staff training - make sure everyone you are working with has something they can participate in (and preferably a choice of options); attend to people briefly at short intervals while people are doing the activity, sometimes just watching what they are doing, sometimes commenting briefly; and when people are doing nothing or if they disrupt the activity, withhold attention apart from an occasional prompt to join in again.

This too conceals a degree of skill required in staff. In order to establish participation a high proportion of instances must be attended to; this is particularly important for people who make only fitful, sporadic or half-hearted attempts to join in. Staff therefore need to keep a special watch for these attempts so that the individual experiences reinforcing consequences as consistently as possible.

There are also several risks staff need to check they avoid. When working with two or three people there is a tendency to notice task completion and to attend to that - so that the attention is contingent upon doing nothing (ie having finished the task some time before) rather than upon participation. Better to offer the next stage or a new opportunity and attend to the person's first attempts to undertake it. Staff may also confuse attention with a kind of special manic effusiveness that grips people when they try to reinforce behaviour. This is socially obtrusive, wears everyone down and, unless there is clear evidence



that it is needed, it is better to deploy ordinary levels of interest and comment on what people are doing.

Finally, staff practice can drift away from the encouragement of participation by contingent attention towards *dis*couraging *lack of* participation, by nagging people when they are not joining in. This may be effective in the short term but it sours people's relationships and encourages staff to blame the people they serve for 'failing' to join in. Maintaining a skilled level of performance to avoid this and the other risks, as with skill in providing appropriate help, requires an open climate of peer review and discussion referred to again in Chapter 11.

Of course attention is not the only possible consequence which might exert a reinforcing effect on behaviour and staff need to remain alert to the possibility of other events playing this role. In particular, simple completion of the task itself may be rewarding, either because of the act of completion and the mastery this demonstrates, or because of the effects it has, or because of being able to move on to the next step. Similarly, for some people regaining access to passivity or stereotyped behaviour may be very important. The relevance of staff attention here is not that it should be used to overlay and obscure these natural contingencies, but that it should work with rather than against them.

Special consideration needs to be given to the use of language by staff in helping and encouraging people to take part in household life. Where people are unable to speak or do not have much expressive and receptive language, it might be thought important to bombard them with speech; this is the assumption behind the use of staff speech style as a measure of quality of care and is consistent with the idea that communication is only likely to be developed as a functional response to environmental demand. However, the best way of presenting such demands may be by short, simple statements - it can defeat the purpose to obscure the words the person can understand with a stream of communication beyond their comprehension. High rates of speaking may simply

distract the individual from task-based cues as well as seeming unnaturally effusive and controlling.

These positions are not necessarily entirely incompatible but suggest that how speech is used depends on the individual person's needs, the task in which they are engaged and the object of the exercise. If speech interrupts or distracts attention to the job in hand, and if completion of the job is the goal, then it seems sensible to restrict the amount of speech used. If the goal is primarily to elicit speech or to maintain a person's attention to the member of staff a much higher rate of talking is appropriate.

The implication for the team of staff providing a staffed housing service is that they must shape their own style of interaction in the way most helpful for each person they support. Since promoting effective communication is typically one of the weakest areas of residential services for people with severe and profound mental handicaps, it is important to draw on the advice of speech therapists and to integrate individualised interventions into the everyday flow of interaction.

## Creating Rhythm and Variety in Everyday Life

This model of interaction between staff and the people they serve provides a general style which can be used to promote staff helpfulness with any kind of activity in any situation. At a broader level of organisation, any household develops ways of reaching decisions between the people who live together to ensure that everything needed gets done and that individual interests can be pursued without conflict and disruption.

The situation in a staffed housing service is the same. But because the people served need staff to help them organise their environment, and because there will usually be more than one or two staff involved in the support team, the need for organisation is even more important and the mechanisms for decision-making need to be more carefully thought out. Given the need to make sure that



everything gets done, plus the goals of structuring activities so that the people served do them with help rather than that the staff do them, and of providing each person with opportunities to choose between activities and decide what they want to do and when, the workload for staff is substantial. They will have little capacity to absorb inefficiencies of organisation.

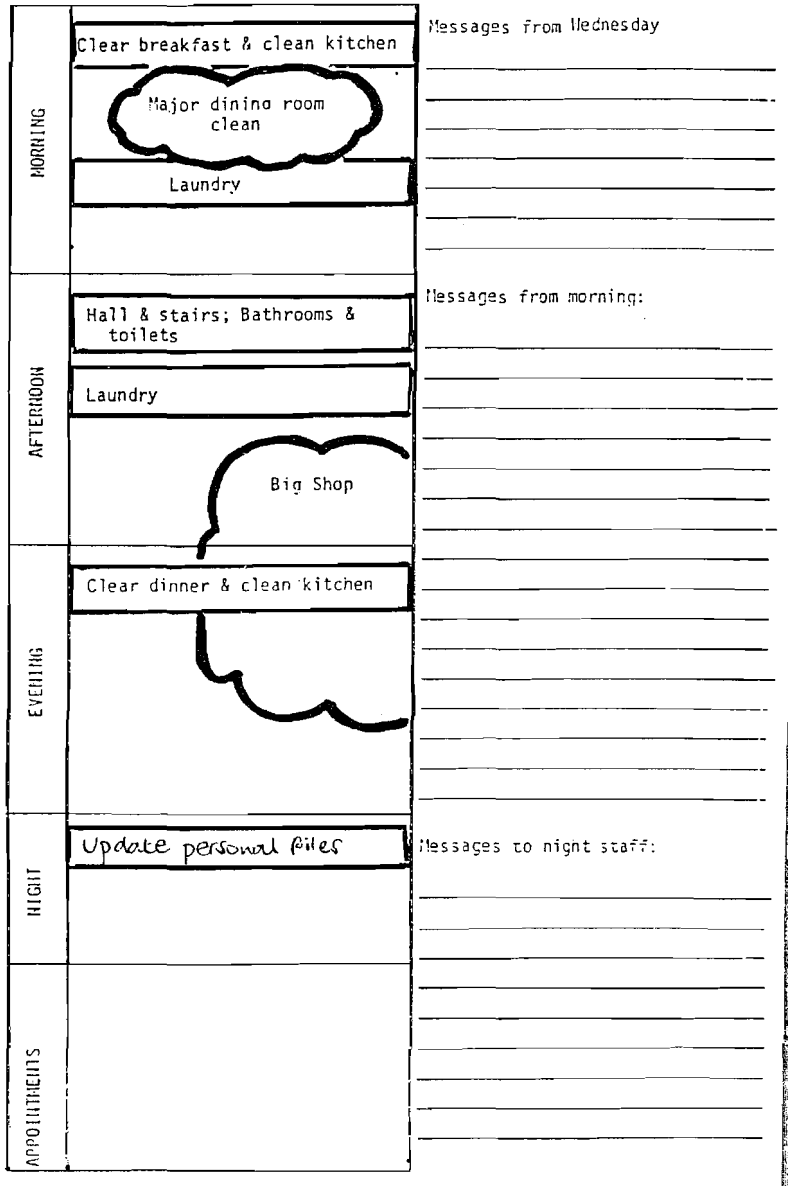
Most households use three kinds of aid to help them organise their communal life. They develop certain rhythms and routines for doing basic tasks so that these at least do not have to be constantly checked on, negotiated about or worried over. They discuss and agree the distribution of tasks and responsibilities frequently and informally; and they write down (in diaries or on notes) things to remember or to communicate to people not present at the time. The same three approaches can be used in staffed housing.

### *Setting Basic Agendas*

The basic framework of organisation is an outline plan of tasks in the week, including those that must be done every day (like preparing meals) and those done less frequently. Of course this plan need not always stay the same nor need the timings be kept to rigidly.

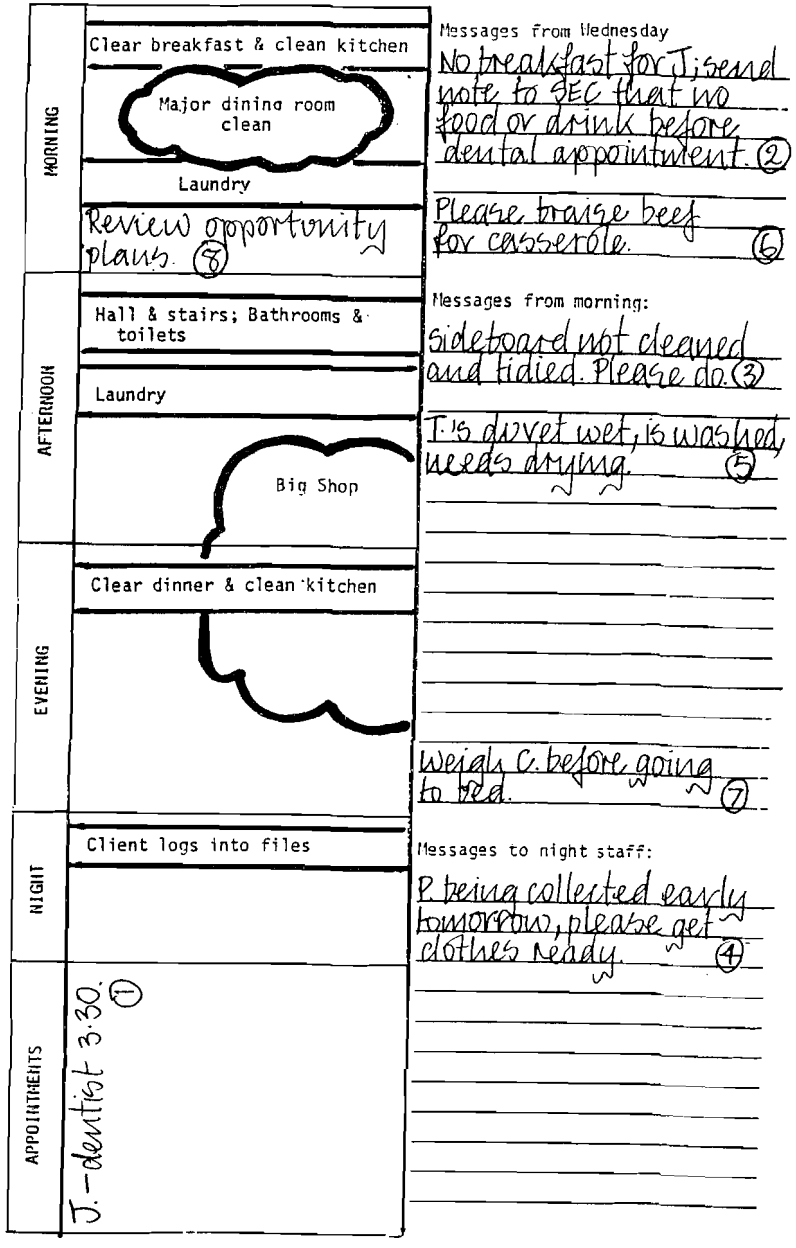
Where all this work is done by one or two people (parents in the family, for example) no written plan may be needed. Where the people living in a staffed house or flat are served by a group of staff, there will probably be a need for a discreet way of keeping track of what needs doing and when. One way of doing this is to keep the plan on seven separate sheets (one for each day) in a folder in a drawer in the kitchen or living room, using the format shown in Example 9.1. On each sheet there is space for the pre-planned tasks, special appointments and space for staff working on one shift to leave messages about where they got up to for the staff on the next. If the sheets are acetate or other wipe-clean plastic, the appointments and messages can be erased at the end of

*Example 9.1* THURSDAY **Daily Timetable (blank)**






*Example 9.2* THURSDAY **Daily Timetable (in use)**



the day for re-use the following week. This avoids being submerged in paper and paying a fortune in photocopying forms.

In Example 9.1, routine daily tasks are listed for each shift in boxes. Tasks which do not happen every day are ringed by 'clouds'. Although tasks are entered at roughly the time of day they usually occur, the timings are flexible. Some tasks (like a major shopping expedition) can occur on different days (depending perhaps on the weather or what else is going on) and this can be shown by making the 'cloud' containing that task straddle shifts or days. The tasks timetabled in this way include all the basic housework (but not meals - people do not usually need reminding about meals) and also household administration tasks including filling in diaries or other individual case records.

Example 9.2 illustrates the use of the daily timetable. At the beginning of the week all appointments for the people served are copied from the house diary on to the daily timetable sheets (1). If the appointment has special implications for the person concerned on that day (such as needing to abstain from eating before an operation), this is written in the space for messages (2). During the week, any new appointments or engagements (such as a social visit to a friend) within the week are noted on the relevant day's timetable. Longer-term appointments are entered in the diary.

Staff use the form to leave messages for each other across shifts. This retains enough flexibility for people to choose what to do by ensuring good communication between staff. Typically there are three kinds of message: those where something usually done at one time of day is not finished and is left for completion later (3); those where incoming staff need to be told about unexpected changes of plan (4 and 5); and those where staff are asked to get something ready for a later shift (6).

Sometime during the week staff will have their weekly meeting when they review their work. The member of staff who writes up the notes of this meeting can add



messages (7) or amendments to the timetable (8) on the relevant day's form.

*Planning Activity*

The weekly timetable sets out a basic framework for day-to-day household activity. In addition to the tasks it lists, there will be a wide range of activities generated spontaneously in the course of the day. There needs to be a way of coping with this spontaneity (to avoid sticking to the same rigid routine) without inadvertently creating gaps when there is nothing for some people to do or conflicts or misunderstandings. Other households do this by talking to each other about what they are going to do.

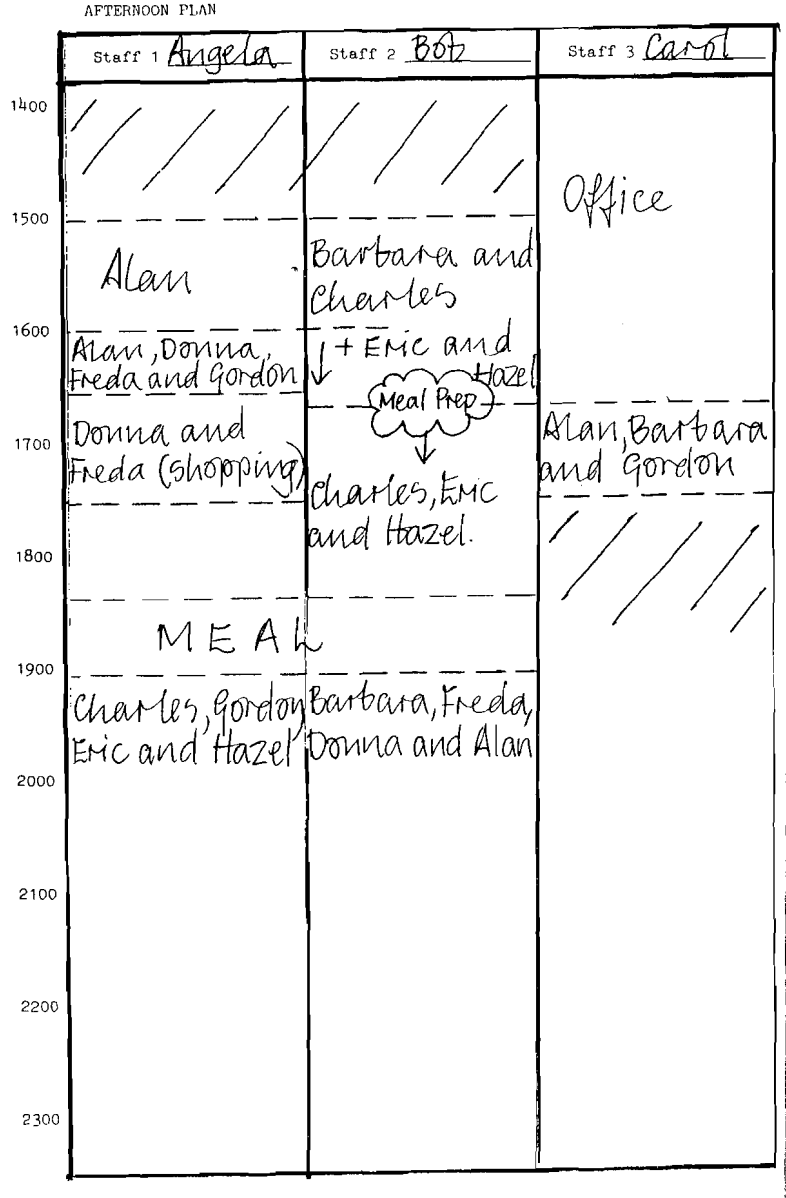
If the staff rota is arranged so that there is a 15-30 minute overlap between shifts, staff can meet briefly both to check over the day's timetable with those staff about to go off duty and to discuss between themselves what they are going to do, which people they are going to help and who is going to be responsible for which tasks. This short 'breathing-space' while the staff on the previous shift are helping the people served encourages staff to think through their work.

Given this opportunity, staff may readily be able to agree a workable plan which achieves the goal of providing opportunities for the people served to undertake a range of activities without periods of enforced inactivity. As an aide-memoire, the kind of 'planning grid' shown in Example 9.3 can be used to help structure this kind of staff discussion. These too can be written on acetate or wipe-clean plastic.

One grid is prepared for each shift on which more than one staff works. The format of the grid provides one column for each member of staff who might be on duty with a timescale in the left-hand margin. As staff discuss who is going to help which people served do which tasks, these are noted on the grid. Mapping out activity in this way helps ensure that staff work is coordinated, that every person living in the house or flat has someone

*Example 9.3*

**Illustration of a Planning Grid (Afternoon)**






available to help them at any time and that activities are properly staffed. Two particularly important instances are meal preparation and trips out of the house. If meal preparation is not sensibly planned all sorts of other arrangements go awry; if only two staff are working with three or four people and one staff accompanies one person out of the house, the range of activities the other three people can do will be limited by having only one staff available to help.

In practice, this process of discussing the organisation of activities on a shift has six parts:

1. Staff need to remind themselves of any specially organised individual activities they will need to help with (such as sessions helping people learn new things or particular ways of responding to difficult behaviour).

2. The daily timetable has to be checked and staff allocated to the timetabled household tasks.

3. Someone has to be allocated to help prepare the meal (if one occurs in the shift) and a decision needs to be made about when the meal will be.

4. Bearing these issues in mind, staff need to work out how they will allocate themselves to help the people they serve. This means agreeing which staff will help which people do which activities. Since this is likely to change through the shift, the transfers of responsibility should be clearly identified to avoid periods when no-one is responsible for helping a particular person. Particular attention needs to be paid to the preferences of individual people served for sequences and schedules of activities, especially so as to give people who cannot tolerate high levels of demand enough opportunities to manage the length of time they face them.

5. All staff on the shift must be involved in this discussion, including senior care staff who may spend substantial amounts of time doing

administrative tasks. This will help ensure that administration is made to fit around the needs of the people served.

6. Typically, the early morning period in the week is very busy and may always follow much the same pattern, even down to the same staff helping particular people. If this is so, this section of the grid need not be erased and the planning meeting can be held just afterwards - although only if this does not interfere with the people served (staff may have worked hard for two hours and feel they need to sit and talk; those people who have not left for work or some other day activity may feel they have been getting ready and now want the real action to begin).

This last point has more general implications. Even within a flexible and varied daily round of activities there are many basic cornerstones of the day which do not change very much. Typically, staff will have different ideas about how these things should be done. In the induction training, it was suggested that time was spent agreeing basic approaches when constructing the first timetable to avoid the people served experiencing abnormal shifts and changes. It is worth continuing to invest some time in the weekly staff meetings to think through and agree common ways of doing these tasks so that changes reflect conscious planning rather than random or arbitrary variation.

### *Leaving Notes and checking Achievement*

The major mechanism of leaving notes for other staff is writing the message on the relevant daily timetable. This gives a single place which everyone needs to look at so that messages do not go astray.

A second function of keeping some written record is to check the extent to which staff are achieving the goal of helping the people they serve undertake a wide enough range and variety of activities. The weekly timetables and



the planning grids do not do this: they are simply planning aids for staff, and it does not necessarily matter if staff do things differently or even do without them, so long as this goal is achieved.

A simple index of participation like that in Example 9.4 can be routinely kept by staff, either filled in at the time or before the end of the shift. For each kind of activity the person has taken part in, a tick is entered in the relevant place; where an activity has been offered and the person has firmly or repeatedly declined to take part, a tick in a circle is used. This information can be used over several weeks to check that no-one is consistently left out of important kinds of activity (see Chapter 11).

This kind of record has no clear counterpart in ordinary household life; the nearest analogue would be keeping a diary. This could be used as an alternative source of information but would take rather longer to complete and to abstract information from. Sometimes a discreet tally of events may just be less fuss than labouring to pretend not to be keeping a check on performance.

### *Flexibility and Variety*

These aids to effective organisation are designed to encourage flexibility and variety in activity patterns by making it easier to make ad hoc changes without threatening the basic framework of activities. Rigid routines and the unthinking repetition of activity sequences for people as a group ('block treatment') may well start as responses to lack of organisation and communication, when changes readily cause misunderstandings and disruption.

The use of a basic framework of activities (the weekly timetable), a mechanism for discussing and agreeing the distribution of responsibilities (using the planning grids)

*Example 9.4*

## Participation Index

Name Mary Week ending 5/6/85

| Activity | Sun | Mon | Tue | Wed | Thu | Fri | Sat | Total |
|---|---|---|---|---|---|---|---|---|
| *Meals (enter B, L, T or Snack)* | | | | | | | | |
| Prepare food | B | | L | L | | | S | |
| Lay table | L | L | T | | | | | |
| Clear table | | | | T | B | | T | 12 |
| Tidy dining room | | L | | | | | | |
| Tidy kitchen | | | | | | T | | |
| *Housework* | | | | | | | | |
| Wash up | ✓ | ✓ | | ✓ | | ✓ | | |
| Load dishwasher | | ✓ | ✓ | | | | | 7 |
| Put dishes away | | | | | | | ✓ | |
| Daily clean | | | | | | | | 1 |
| Weekly clean | | | | | | ✓ | | |
| Hand laundry | | ✓ | | | | | | |
| Loads washer | | | | | ✓ | | | |
| Unloads washer | | | | | ✓ | | | |
| Put clothes out | | | | | ✓ | | | |
| Bring clothes in | | | ✓ | | ✓ | | | 9 |
| Uses drier | | | | | | | | |
| Irons clothes | | | ✓ | | ✓ | | | |
| Puts clothes away | | | | | ✓ | | | |
| Shopping | | ✓ | ✓ | ✓ | | ✓ | ✓ | |
| Puts shopping away | | ✓ | ✓ | | | ✓ | | |
| Receive visit | ✓ | | | | | | | 10 |
| Gardening | | | | | | | ✓ | |
| DIY | | | | | | | | |
| *Other* | | | | | | | | |
| | | | | | | | | |



## Participation Index (cont.)

*Trips out (enter initial of staff accompanying)*[1]

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Cultural or | | | | | | | | |
| Leisure event | | | | | | S | | |
| Formal recreation | | | | | | | | |
| Meal out | | | | | | | | |
| Pub/Cafe visit | | | M | | | | | |
| Visit friend/rel | S | | | | | | | 4 |
| Visit staff home | | | | | | | | |
| Other (eg hair) | | | | | | | | |
| Stay overnight | | | | | | | | |
| Car journey[2] | | | | | | | | |
| Walk[2] | | | | | | | | |
| Public transport[2] | | | | | | | S | |
| Work | | | | ✓ | ✓ | | | |
| Education | | | | | | | | 2 |
| Day care | | | | | | | | |

*Other*

*Professional consultation (enter details below)*

*Who visited the individual this week (social or professional)?*

✓

*Who did they visit (social or professional)?*

Sister.

1 If an outing included more than one major purpose (eg shopping and a library visit) include them both.

2 Only enter trips if there was no other purpose to the outing.

and a common method of leaving messages and checking achievement allows for:

1. Daily variation of routine activities: variation can be planned by revising the day's timetable and ad hoc alterations can be communicated to colleagues by writing in the 'messages' section.

2. Individualisation of activity: the planning grids focus discussion on what each person served will be doing at any time and who among the staff they have immediate recourse to for help.

3. The involvement of all the staff in actively deciding the organisation of the day.

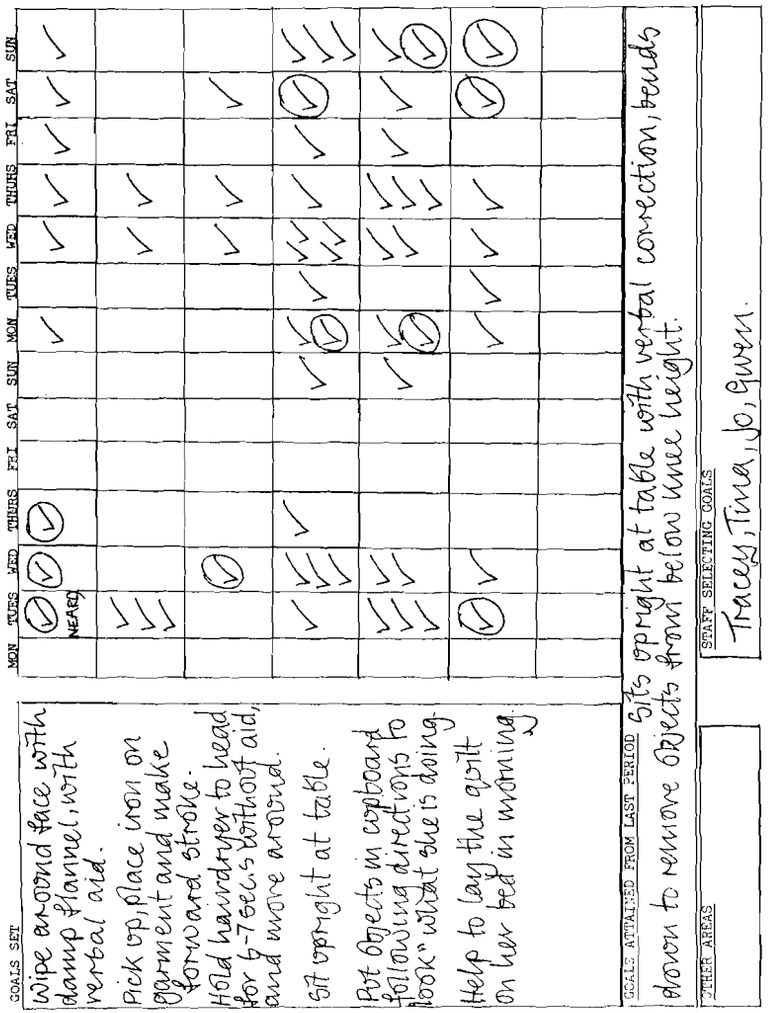
As well as variety, it is important that the range of activities each person experiences is always being broadened to discover new interests and opportunities. Guided exposure to new opportunities often also leads to more incidental learning, particularly in areas in which staff have not necessarily expected to see progress. This can be achieved by building into the planning of activities, instructions or reminders to staff to provide particular opportunities for an individual sufficiently frequently for them to have a chance to find out what is involved and whether they are interested in it.

This kind of 'opportunity planning' is an intermediate stage between organising activities so that people can join in at their current level of ability and the kind of precision-teaching referred to later; it sets up the opportunities but does not prescribe how staff should help people engage in them. Example 9.5 shows a simple record form that can be kept in the individual's folder and used to remind staff of opportunities they should create when they plan the day, together with space for them to record whether they remembered or not. As an alternative, the goals could be written on the day's timetable ("remember to set up three or four telephone calls") and completion could be written on the participation index (Example 9.4). How often the list of opportunities is reviewed and by whom can vary;



*Example 9.5*

**Opportunity Plan**



individual staff on each shift can take a special interest in one person's opportunities (like a keyworker system) or they can be decided at the weekly staff meeting.

In everything written above about creating rhythm and variety the assumption has been that staff are the people constructing each day's schedule of activities. Clearly an important goal is to make the organisation of activities responsive to the needs and wishes of the people served and to maximise the extent to which they determine when and how things are done.

The measures set out in Chapter 1 apply just as much to activity organisation as to anything else. This means setting up choices for people, giving feedback to them on their choices and particularly following through with decisions made by the handicapped person so that they experience the consequences of their choice. Above all it means gradually extending the difficulty of choices so that people are not dumped into difficult decisions where they may choose a bad course of action.

Many people will be able to play a part in the decisions about timetabling and planning what happens each day, so that instead of these being staff-centred activities they approximate the natural situation of people who live together working out what they want. Pictures or photographs can be used to help involve in the discussion people who have difficulty deciding in the abstract.

## Extending Individual Experience

The provision of a wide range of relevant and interesting activities, well-organised and with support from staff arranged in the most helpful and encouraging way, will in itself do a great deal to help people develop their own abilities and manage problems they have. But many people with severe and profound mental handicaps will have additional needs which are not met by this kind of optimally supportive environment. In particular, people will have needs to learn new things which take more teaching than the incidental strategies outlined above;



some people will have problems of not being able to control their own behaviour, which interferes with their access to other activities and may threaten their future; and some will have major physical handicaps or medical problems. To fail to respond to these needs, to pretend that they are not there, is as grave a disservice as neglect on an institutional back ward.

Some people argue that these special individual needs should not be met in a 'home' setting; that they disfigure the homeliness of the service and should be done in colleges or in hospitals or clinics. This is easily and appropriately accomplished when the need is met by short-term interventions elsewhere (examples would be dental or curative hospital treatment) or when the handicapped person concerned can readily generalise their learning to new settings. But in many situations the need is only effectively met by long-term intervention in the living environment in which the person spends their time. The task for the service agency is therefore to deploy the highly individualised interventions needed over the long term in a way which, as far as possible, is unobtrusive and fits in with ordinary home life.

### *Special Help in learning New Skills*

For most kinds of task, most people learn best if they have clear information about what to do, repeated opportunities to try to do it ('little and often'), consistent feedback and help and, if they achieve enough success (even with help), to maintain their enthusiasm and avoid discouragement.

There are a large number of job-aids designed to help staff working with people with severe and profound mental handicaps to achieve this kind of teaching. The most widely known in Britain are the Portage Guide to Early Education, designed for pre-school children living with their families, the EDY scheme for children and the Bereweeke System designed for use in residential and day settings with checklists for children and for adults. The

Bereweeke System is outlined below to illustrate the kind of approach required.

The Bereweeke System delivers a number of short teaching sessions, usually in a massed-trials format, to an individual each day. The conduct of each session is prescribed on an *activity chart* (Example 9.6) which includes a record of performance and is based on a carefully-worked out *teaching strategy*. The strategy relates to a *long-term goal* derived either from assessment (where personal priorities are not already known) or from the individual programme planning system.

Each activity chart lasts one week and deals with one step in the teaching strategy. The person preparing it (usually, at the beginning at least, an experienced member of the staff) takes care to give a clear account of how to help the person through the session and will also explain the details to the two or three staff on different shifts who will use it. During the week they will also watch some sessions to get a clear idea of how well the teaching is going. At the end of the week they use the record of progress on the chart to decide whether to write a new chart for the next step, keep the same chart for a second week or try a different approach to the same step. As with the aids to organising activities described above, the Bereweeke System includes a simple tally of overall success of teaching which can be used to keep track of progress.

The strength of this kind of system is that it provides a framework for special teaching in the home setting without taking more than a few short periods each day. To use the system effectively does require that staff are quite skilled at delivering help and encouragement in the ways already discussed, and also that the person who constructs the teaching strategy has the creativity and imagination to develop optimal approaches. This is a particular area of weakness among most front-line care staff (and some professionals too) which may need extra attention. Good written sources of guidance are given at the end of this chapter.



*Example 9.6*

**Bereweeke Skill-Teaching System: Activity Chart**

| | |
|---|---|
| Name *John S* | Week ending *8 Aug* |
| Long-term goal *J. will use launderette once a week on his own* | |
| Teaching target *J. will cross the road safely with reminders 15 times a day* | |
| Criterion *15/15 two days running* | |
| Place of sessions *any side roads near unit* | Times of sessions *any time in daylight* |
| Materials and preparation *Take J. for a short walk 3 times a day; vary the routes; cross five roads on each walk.* | |
| Instructions (what to say and what help to give) *1. When you come to a side road say 'Stop at the kerb' about 10 feet from the kerb. Wait for J. to stop first.* *2. Then say 'You tell me when to cross' and wait for him to say when.* *Don't distract J. by talking about anything else while you're teaching. Chat during the rest of the walk.* | |
| Correct response *1. J. stops at the kerb.* *2. J. says 'Cross now' when there is a big enough gap in the traffic.* | |
| Reinforcement for correct response *1. Just say 'That is good' and go on to 2.* *2. Tell J. that he's done it right - mention his success to other staff (when J. is around) when you get back.* | |
| Correction procedure *1. If J. steps off the kerb say 'Wait', then go back a few yards and do it again yourself to demonstrate; then ask him to copy.* *2. If it's not safe say 'No', point out the danger and say 'Try again'. Tell him when to cross this time.* | |
| What to record *Score out of 5 roads crossed where 1 & 2 both correct (eg 4/5)* | |

| Number of sessions walks | Days | Staff |
|---|---|---|
| 3 | Fri | DS |
| 2 | Sat | NW |
| 1 | Sun | NW |
| | Mon | NW |
| | Tues | DS |
| | Weds | DS |
| | Thurs | DS |

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Problem behaviour has the special characteristic that it evokes in staff feelings of despair, anger, guilt and blame. Defining what the problem is, whether it really matters, what causes it and how it should be dealt with become political questions in which different people have vested interests. This means that no simple set of guidelines can or should be offered as a 'cook-book' from which staff select interventions. To do so typically leads people to ignore contextual factors that may explain someone's behaviour as reasonable in the circumstances and to employ escalating intrusive and punitive contingencies to suppress the problem.

The alternative starts from the assumption that a person's behaviour is reasonable, rational and understandable and proceeds to search for what makes it so. This process of *functional analysis* leads to identifying the outcome(s) the individual needs and currently achieves using the problem behaviour. The treatment strategy is then to find ways of securing the desired outcome for the person without them having to deploy the problem behaviour.

The desired outcome may be something the person positively needs, like affection or attention from other people, getting to do a preferred activity or making someone pay attention to helping them properly; or it may be escape from something the person cannot take, like staff asking them to do something or being in a crowded or noisy place. Sometimes the outcome may be an internal biological state (like getting relief from pain or, perhaps, experiencing high levels of arousal); but the available research suggests that in many cases the outcomes the person wants are in their immediate environment.

Note that the starting assumption is that whatever the person gains as the outcome of problem behaviour is a legitimate want or need. It does not matter if staff feel that one person craves 'more than their share' of attention: the fact that the individual has to use problem behaviour (which usually incurs at least some penalties)



shows that, for them at this time in their life, attention is desperately important. The goal is not immediately to insist they get by with as little attention as anyone else but to provide as much affection and interest as they need without their having to resort to the problem behaviour to get it. This means making affection and attention contingent upon other more appropriate behaviours and supplying lots of it (even when there is little 'other behaviour' to attend to). Attempts to make the person 'make do' with what others get will likely produce an escalating series of new problems as the person desperately searches for a strategy to get the outcome they need at the required level.

This also applies where the outcome the person needs is more obscure. If someone uses non-compliance and disruption to gain time gazing at flickering patterns of light on a window-pane, the goal is to enable them to get access to this through other behaviours, not to reduce their access. Only once the individual concerned can gain their desired outcome as much as they want through a more appropriate route does it begin to be possible to reduce their dependence on this source of satisfaction. It seems that a crucial component here is to increase the person's competence and confidence in other areas of their life where they can access similar outcomes.

All of this process requires sensitive and skilled investigation and interpretation beyond the competence of most professionals (including psychiatrists and psychologists) and care staff at the moment. The strategies used in institutions have been different: to tolerate the behaviour if at all possible; or to suppress it by restraint; by making the person live in a barren, controlled environment; or by using drugs to reduce their level of activity. Some problems are genuinely difficult to understand and their management tests the absolute limits of our knowledge about human behaviour.

Given these circumstances the organisers of a staffed housing service and the staff supporting people in it need to try to develop their own skills while not giving up on people and letting them be sent back to institutions. When

this does happen it remains important to question the naive interpretation that the individual 'cannot live in the community' and is 'getting treatment in hospital'. If the latter was ever true the task would be to copy the successful methods in the community; in practice return to hospital does not usually involve treatment but containment.

### *Special Help in overcoming the Effects of Physical Handicap*

It is not only people who have challenging problems of behaviour that find themselves likely to be excluded from an ordinary life in the community. Many service planners believe in setting up special units for people who are blind, or deaf, or deaf and blind, or who have major physical handicaps and need to be cared for by staff who can detect impending difficulties and take appropriate action. Because the numbers of people with such handicaps is small, the special units would serve large areas; because they are proposed by people with a health service background they would be designed like small hospitals and they would usually be sited at a hospital (perhaps a general hospital). Thus they would replicate many of the undesirable features of the traditional long-stay mental handicap hospital.

By grouping together people with the same high levels of demand for staff help, unbearable demands are made on staff at crucial times of day, leaving them tired when they are needed to help people join in household and community activities. Special units can, therefore, conspire against enabling individual participation.

So, even if special treatment cannot be provided locally because local services have yet to develop the competence in that particular area, there is a balance to be struck between meeting the special needs someone has and meeting the other needs they have in common with everyone else. Even if the local service cannot offer



everything, it still may have more to offer than a special unit a long way away.

A major goal for services providing staffed housing for people with sensory or motor handicaps is to find ways of enabling people to control their immediate environment - to decide where they are going to be, to summon staff when they want them, to communicate their needs or to satisfy them for themselves. Staff who support people with major sensory handicaps in addition to severe or profound mental handicap will need special advice about the physical layout of furniture and equipment or methods of communication. For people with major physical handicaps the range of equipment available to people with similar disabilities who are not intellectually disabled, could increasingly be made available, using computer assistance to remove sources of error.

For example, workers in Britain and Sweden have provided electric wheelchairs which follow a track (made simply of adhesive tape) around the living environment. This removes the potential error of driving the chair into the wall, and permits people with multiple handicaps, who would otherwise be left helpless in a wheelchair, to move around and choose where they would like to be. A similar adaptation in Sweden provided a switch on each person's wheelchair which any movement would switch on to sound a buzzer; this could only be switched off by staff coming to the person, providing the basis for the handicapped person to summon staff when they wanted.

This kind of innovation is in its infancy. For people with profound mental handicap and major motor handicaps, it is likely to revolutionise their ability to control their environment and may be a much more significant use of computers than the 'learning games' developed for special schools.

## Further Reading

The quotation which starts the chapter is from the film *Breaking through* (Toronto: National Institute on Mental Retardation, 1982).

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# 10. Social integration

A central component of the idea of normalisation is that the social integration of disadvantaged people is an important part of the service mission. Interpreted in terms of the personal relationships of individuals, the aim is that each person served should have a wide range of friends and acquaintances, drawn from among the majority of the population as well as any who happen to be disabled too. This chapter describes the measures staff can take to help the people they serve to enter and keep such a network of supportive relationships.

The first benefit to be sought by this route is friendship. A good service would help protect and enhance the friendships a person has, and would encourage the maintenance of a range of friendship relationships varying in levels of intensity and scope. The service would recognise that a sense of companionship with others is a basic need of people to which it ought to respond. But this kind of special, intimate relationship with another person is usually thought of as having to do mainly with the extent to which individual personalities are similar or complementary, and so the aim of friendship might be achieved if people with mental handicaps drew their friends only from others with the same disability. If social integration implies having relationships across group boundaries this aim need not involve social integration at all.

Normalisation offers two other rationales for social integration. The first is that having relationships with people in the majority alters their perceptions so as to produce better treatment and greater protection of personal rights and interests than when the person is seen only as a member of the minority group. This could be for several reasons: other people might not associate the individual with their least helpful stereotypes and beliefs about people with mental handicaps; or the multiplicity of roles in which they know the individual might counteract



low expectations in the 'handicap' role; or they may not be able to tolerate the unfairness of the treatment the individual gets when known personally (whereas they can cope with this conflict when people are 'out of sight and out of mind').

This reason refers to the direct consequences of integration as experienced by the individual concerned in their own lifetime. Normalisation also offers a rationale which looks at social integration on a longer time scale. This is the idea that a social minority (like people with mental handicaps) is more likely to be protected against discrimination and disadvantage if many members of the wider society have personal relationships with and experience of members of the minority group; that when, for example, there is public debate about the level of resources to be provided specially for the minority, people will be more sympathetic if they know members of the minority group themselves. The evidence for this is limited and current social-psychological research suggests that the way individuals behave to each other may not have too much to do with the relationship between social groups: so that it is possible to maintain prejudiced views about a group even when participating in some personal relationships which cross the group boundary. But combined with the value of integration at the individual interpersonal level, the possibility of benefit at the societal or intergroup level implies that a responsible approach is for a service agency to foster the growth and maintenance of supportive personal relationships with a range of people in the wider community.

One immediate implication of this focus on relationships at the personal level is the importance of individualising what the service does to promote social integration. Where people are grouped together the service risks eliciting stereotypes and prejudices employed by the wider community in relation to disabled people, or people with mental handicaps as a whole. In so far as people are seen and met as individuals this risk is reduced and there is a greater chance that similarities between the handicapped person and non-handicapped people will

become more salient than differences. This means that there really will be no place for some of the traditional ways of involving voluntary workers such as leagues of friends or the 'adoption' of a whole household by a commercial, community or service organisation. Where possible, the service agency needs to channel these expressions of goodwill into individualised forms; where this cannot be done it may be possible to deal with them at agency level (turning a potential league of friends for one household into a support group for the mental handicap team in the service agency). In some cases the agency will have to decline the involvement of such a group altogether, where the group insists on arrangements which would be stigmatising for the people served.

None of the reasons given above why social integration is an important goal describe benefits which will necessarily or automatically occur just because people live in the community. Studies of people with mild or moderate mental handicaps show that such people can be just as lonely and isolated in community settings as can other people. In a service for people with severe and profound mental handicaps, in this as in every other goal area, the service has to act to realise the opportunities created by community placement.

Just as in other areas of life, there is a balance to be struck here between individual choice and the importance of keeping opportunities alive. Some people will start their life in the community withdrawn and isolated and may resist or decline attempts to make relationships: after long experience of being ignored, rejected and passed by this should be no surprise. But there is no choice without a range of experience; and it is the responsibility of the service to repair the damage done and to try to provide good experiences of relationships to counter-balance the bad. Some people may eventually opt for a quiet and relatively solitary life and this can be a reasonable choice just as it is for anyone else. Even then, though, the service has some responsibility to help the individual maintain enough of a rudimentary social network and of their own social skills and personal supports that they can



change their mind later (having enough experience to keep alive the options).

The rest of this chapter is divided into two main parts. The first deals with building a network of relationships with friends and acquaintances. This deals first with creating opportunities to meet people and outlines the range of activities and situations to which staff ought to help the people they serve gain access. It also discusses the mediating role of staff in facilitating interaction between the individual handicapped person and other people. The second part of the chapter deals not with building relationships but with maintaining them. It outlines the range of issues involved in nurturing a network of relationships of different types and styles, including the way staff can review their effectiveness in helping the people they serve develop and maintain such a network.

## *Building a Network* of *Friends and Acquaintances*

### *Creating Opportunities*

One of the strongest indications for friendship is nearness; people are more likely to get to know those who live in the same street, work in the same place, use the same shops or join the same clubs. Repeated encounters in the same situation lay the basis for developing relationships in that they identify individuals as having something in common and they provide opportunities for social and practical exchange. Note the significance of this for much current practice in services for people with mental handicaps: if people spend most of their time with the same individuals, segregated as a group in all activities of daily living, they can only be expected to develop relationships largely or entirely within that group.

The first decisions about the service which help or hinder friendship are, therefore, the basic planning decisions about location and model of care. If the people

served by staffed housing are to build on their family relationships to make friends they need to live near enough their families. If they are to meet people over and over again in ordinary situations they need

1. to live near shops and amenities used by other people
2. enough staff to help them make use of these opportunities individually
3. devolved budget control to spend their money locally
4. not to have 'hotel' services provided on an institutional model

These planning decisions provide opportunities for individuals to have repeated access to a wide range of situations in which they meet other people. Achieving this goal involves attending to the breadth and variety of types of situation which staff help each person encounter, the extent to which the situation elicits interaction between the people involved, and the consistency and repetition of these opportunities.

Broadly speaking, opportunities arise in four domains: residence, shopping, leisure and work. The residential domain offers opportunities to develop acquaintanceships through the upkeep and repair of the house, garden and car, and through communal services such as keeping the property and street frontage tidy, clearing leaves or snow or taking in mail or deliveries for neighbours. Most people aspire to at least a passing acquaintanceship with a few neighbours so that they can call on them for occasional help, such as borrowing tools, watering houseplants or feeding pets during holidays. Shopping provides opportunities both in the direct transaction between purchaser and shopkeeper and between regular shoppers. In each case, there are better opportunities when an individual patronises the same shop over time and the shops are relatively small. This makes it more likely that they will be served by the same person or one of a small group of people and that they will get to know



other people using the same shops, especially if they also meet in another context (such as work or home). The use of leisure facilities and other social amenities includes attending educational classes and courses, clubs set up around special interests like riding or photography or around particular social groups such as young farmers or business-people, or the use of facilities such as swimming-pools, cinemas, dance-halls, theatres and parks.

Not all types of activity provide the same opportunities for making social contacts with other people. Solitary activities like spectating at a sporting event or watching a play at the theatre provide less reason to talk to others than social activities. Many people prefer to go as a member of a group to the theatre or cinema in order that they should have someone to share the experience with. Other activities, like singing in a choir or playing sport as a member of a team, where there is some cooperative element in the task requiring the people participating to interact closely together, provide more opportunity to meet and get to know other people.

Another relevant concern is that some kinds of activity will highlight disability and difference, particularly where the nature of the individual's disability impairs achievement of a group goal in a competitive situation: no-one wants to be the member of the team who always lets the side down. This means finding activities or situations which involve cooperation between people, but where there is no competition between one group and another in areas that might draw attention to an individual's disability. Making purchases in shops, for example, allows the shopper to participate in real social exchange with the shopkeeper by paying for goods, in a way which need not show them as less competent or important than other shoppers. This is an important contrast with the situation in, for example, poor-quality environments, where it can be very difficult for a visitor to remain interested in the individual they came to see because there is nothing to connect two people together - no common purpose, nothing to talk about, nothing to

share. Real-life activities provide a real basis for interaction.

Thus it is important to ensure a balance between situations which demand some degree of cooperation, emphasise the handicapped person's competence and encourage others to see them as a legitimate member of the group and those which do not. It is also crucial that the service is organised to ensure that staff help the individual achieve enough consistency and repetition in potential social situations to maximise the opportunities for actual contact. The aim is to see many of the same people each time, and to see them often enough that attendance or non-attendance is noticed. This certainly means going to the same place (shopping in the same stores, booking the same tennis courts) but it may also mean going at roughly the same time (such as swimming at the same time on the same days each week).

If the service is organised to assist people, no matter how severe their handicaps, to participate in household activity (and therefore does not remove opportunities to garden, clean the car, shop or go to the park), involvement in social activities outside the home should be a natural extension of household organisation. It should not be necessary to have to plan each person's involvement in everyday activities through the individual programme planning system. Individual programme planning does have a role, however, as a back-up in identifying possible activities or situations which do not arise in the course of everyday living, such as developing new areas of interest (joining a coin-collecting club or a choir); it is also likely to be the main mechanism for stimulating the search for alternatives to traditional day care.

Work is so important that it deserves special mention. It plays if anything an even more important role than the other domains in creating opportunities for making contact with other people. Probably the single most important contribution the service can make to the welfare of a person with severe or profound mental handicap, apart from providing staffed housing to enable



them to live in their community, is to help them get and keep a good job. A good job provides a central purpose which makes much planning for the individual easier and more straightforward: it provides reasons to do things, to learn new skills or organise family life in particular ways much more clearly than through sitting down with a group of professionals to discuss the future in an individual programme plan meeting. A good job also provides a major source of stimulation and interest and the money to broaden one's experience and achieve greater independence. A good job provides many opportunities for getting to know other people: the job itself may require cooperation, as when a team of people work together on a task like erecting fencing or running an assembly line; or it may involve meeting other people in the course of doing the job, such as going to stores to get new materials or eating in the staff canteen; or there may be ancillary social activities organised through a staff club, or special recreation facilities provided to employees.

Needless to say, there are formidable obstacles to obtaining a good job for people with severe and profound mental handicaps. Jobs - any kind of jobs - have become increasingly hard to find because of economic recession. More and more jobs require skills that, by definition, people with severe and profound mental handicaps find very difficult to learn. Competition for jobs retards the improvement of working conditions, so that many of the jobs available do *not* provide the benefits described above - they are instead boring, repetitive, badly paid and they have no future. But most of all, services for people with severe and profound mental handicaps have defined their clients as people who are not worth trying to find a good job for, ignoring both the evidence about what people have shown they can learn given the best teaching and different ways by which it might be achieved, such as through job-sharing with people who can act as a facilitator (or 'foster-worker').

Increasing interest is being shown in making services respond to these issues rather than continue to provide

traditional day care centres and there are a few individual examples of people with severe mental handicap getting a good job instead of a day centre place. This is likely to be a major area of interest to which a service focusing initially on housing as its major priority will inevitably have to respond as the gap between the achievements of good residential services and old day care services becomes apparent.

### *Facilitating Interaction*

Repeated exposure to the same situations may itself be enough to prompt social encounters with other people; people served by a staffed housing service will often, however, need help to make use of these opportunities. Simple presence, even under optimal conditions, may still not be enough to enable many people with severe and profound mental handicaps to initiate or respond to first opportunities in a way which increases the likelihood that passing comments or greetings will be turned into acquaintanceships or, eventually, friendships. For those people able to deal more effectively with social situations on their own, social skills training backed up with advice, feedback and plenty of practice is likely to be the preferred method of helping people take advantage of opportunities as they occur. For people who use staff to help them in most or all social situations, staff can play an important role in facilitating helpful interactions involving the individual they serve.

Many first contacts are likely to arise because in some sorts of situation most people speak to the people they are with (in a small group together, for example, as in a shop waiting to be served or in a lift). These contacts are initiated mainly on the basis of assumptions each person makes about the other in terms of their appearance and behaviour - whether this is the sort of person one could accept a relationship with, whether there are unacceptable risks of being embarrassed or offended and whether contact would be seen as acceptable (rather than as



interfering, for example). Unattractive or unusual appearance or behaviour presumably would predispose towards fewer social contacts, so that attending to good looks and competent performance is an important first task.

In the first and in subsequent stages of acquiring relationships, the role of staff in facilitating helpful interactions can involve several components. First, staff can help in interpreting between the person they are with and the other party. This might be interpretation in the literal sense, re-phrasing comments or remarks made by one so that they are understandable by the other, as when using sign language or when one person's speech is indistinct or too difficult for the other person to understand. Or it may be explaining on behalf of the person being accompanied how that person communicates - whether to touch them to gain their attention or how long to wait for a response before trying again.

Second, staff can help by completing or augmenting responses made by the handicapped person; this might involve supplying the right change to facilitate a purchase, prompting for the right thing to say, or helping do the relevant activity. This helps to show the individual as competent and also ensures the smooth flow of the activity in the situation. Staff working with people with severe and profound mental handicaps can identify opportunities for involvement in much the same way as they identify opportunities for involvement in household tasks - analysing the parts of the activities involved which the individual can do without help and helping them through the parts they cannot do independently. A similar set of criteria can be used by staff to review their own performance (Example 10.1); this is not so much as a way of gathering information about what routinely happens as about stimulating discussion.

A third important way staff can facilitate interaction is by using opportunities for incidental teaching, both for the handicapped person and the other people they meet. There will be opportunities for incidental teaching not only in the tasks encountered in the activity (whether

*Example 10.1*

Checklist for facilitating participation in social situations

Breaking the activity into manageable parts

1. What are the range of tasks or steps which go to make up the activity?
2. What is the least obtrusive level of help the person needs to be reasonably sure of completing each task successfully?
3. Did the person get the right level of help?
4. Were they successful at each task?

Facilitating interaction

5. Did staff 'fill in' bits of the task the person could not do?
6. Did staff help the person they were with interact appropriately with the people they met?
7. Did staff help the people met during the activity to interact appropriately with the handicapped person?
8. Did staff focus the conversation on individual strengths of the person they were with and their successful performance?

*This checklist can be used to prompt discussion of how to help the people served make the best use of opportunities in the community. One person can describe their experience of helping someone on a recent outing and this can be used to focus the discussion.*



shopping or playing a sport or clipping a hedge) but also in the social aspects of these situations (smiling and greeting people, attending to them when they talk, and so on). For the neighbours or others involved in the interaction, staff can both give direct instructions where this is helpful in reducing anxiety or uncertainty - "just hold it out and he will reach for it in a moment or two" and also staff can model appropriate ways of interacting with and talking to the individual being accompanied, so that the other person can see clearly how they should behave.

Once these early contacts are made, usually in the form of asking for or providing some kind of service (directions, opening a door, telling the time) or commenting on some common issue (the time it takes to get served in a shop, the weather, the performance of participants in a sporting or other spectator event) the opportunity is presented for either participant to withdraw without embarrassment or to continue the conversation. Here staff can help the person they are with to get the right balance between intimacy and privacy (steering the conversation away from personal topics, helping both parties judge the appropriate use of touching or closeness) and, for those people who have difficulty showing a response to contact attempted by others, interpreting responses to give feedback to the other person.

Right from the start it is important to help the handicapped person overcome the use of stereotypes by the people they meet. People are bound to use stereotypes until they have more information to go on: but since the stereotypes of people with severe and profound mental handicaps are so unhelpful, the chances of developing a fruitful relationship with some of the people met regularly depend on breaking through to a more individual, multi-faceted relationship. Staff can help do this by modelling an appropriate relationship (by including the person they are with in any conversation they take part in, by deferring to their choices and preferences when appropriate, by talking to them as an

equal), by highlighting competent performance that challenges traditional views about mental handicap (setting up the level of help so that the individual can control the situation and achieve what it demands) and by giving direct information - particularly when people have trouble speaking for themselves ("Mary doesn't look at people much but shk can pick things off the shelves given a label to match" or "People don't think Tom likes music but he's enjoyed both the concerts we've been to this month").

Where staff accompany individuals into the same social situations regularly, they themselves will begin to make contacts in addition to any that the person they are with engages in. They will address the same issues as outlined above, on their own behalf. Staff should be clear that this is acceptable - because they can act as an intermediary for the person they are with and getting to know people through intermediaries is a common and very effective way of extending one's social network - but that they should share their own opportunities and contacts with the person they are with at the time, rather than consign them to the sidelines.

Since a common fear of people speaking to those they do not know in public situations is that they may be embarrassed (for example, by the person they approach responding too familiarly or by their being unable to disengage when they want), it is important not to force these early tentative encounters, but to allow them to develop naturally. As for anyone, no doubt some relationships will grow quicker than others, and some - perhaps the majority - will not become anything more than a passing acquaintanceship.

Probably the major concern of staff in helping the people they serve get to know other people in a range of social situations outside the home is the difficulty of helping an individual manage seriously disruptive or embarrassing behaviour in public. In developing a strategy for weakening or replacing inappropriate behaviours that limit or deny a person's access to important social experiences the same issues arise as discussed in the last



chapter: the need for a general milieu which sustains appropriate behaviour, clear guidance to staff as to what to do when problems arise and a long-term plan for tackling the problem in a structured way - all worked out in the context of a careful analysis of the function served by the behaviour, rather than a cook-book solution. It is, however, important to address the issue of how to cope with problem behaviour when it actually occurs, rather than hoping that effective management in the home will automatically generalise to public settings.

An important component of a management strategy in public rather than at home is that the guidance to staff on what to do when a problem actually arises, needs to include guidance on what to say to passers by or other people present. If someone sits down in the street or on the floor of a shop, for example, and the planned staff response involves waiting next to the person without interacting, the member of staff - especially if they look young and inexperienced to many members of the public - will need to explain what they are doing and that they are in control of the situation. It may well take some discussion in the weekly staff meeting and some practice for staff to be able to respond in a friendly way to offers to call ambulances or the police, or to offer advice on wrestling holds, from well-intentioned passers by, at a time when they themselves are likely to be tense and worried. When something embarrassing does happen in a shop or similar place, it makes sense for the member of staff involved to call back later that day or the day after - not to apologise but to thank the shopkeeper for their helpful forbearance at the time. Ensuring that the same staff does this avoids them feeling that another member of staff is having to pick up the pieces, or giving the impression they are seen as incompetent to the shopkeeper. Maintaining an emphasis on gratitude for good aspects of shopkeeper performance is more constructive than opening up the option of ruminating together on all that went wrong or the problems of working with the handicapped person, with their attendant risks of victim-blaming.

In practice, if the social and practical costs of disruption are met by the skilled and timely action of staff who deal with the issue in a matter-of-fact, unembarrassed and non-defensive way, many incidents can be tolerated for long enough to work through them. Then the improvement shown by the individual can itself set the occasion for comment and (for both the handicapped person and their staff) appreciation.

## Developing and Maintaining Existing Relationships

The same staff skills apply in helping people develop and support their existing relationships. As people get to know each other better, there may be less need for staff to interpret between them, but there will still be some need to help the handicapped person to carry out the tasks and activities which the friendship involves. This will include helping the individual complete the minor reciprocities which keep a relationship alive - whether through joint activities or visits, providing hospitality at home, correspondence (including photographs or postcards), telephone conversations or the exchange of gifts and cards at festivals. Similarly, the opportunities for incidental teaching remain - in obvious examples like showing friends how best to communicate their needs or wishes to the handicapped person but also in areas like showing a shopkeeper how to give enough help for someone they know to complete purchases without a member of staff on the premises.

It is perhaps not surprising that people who have been deprived of a range of relationships sometimes invest heavily in the one or two they have, threatening them by imposing too great a strain. If a visit has to be postponed at short notice and the individual concerned weeps for hours, then their friend may begin to wonder whether they can continue to meet such an intense level of emotional demand. Rather than follow the common injunction to staff and others "not to get too involved", it would be more appropriate for the service to help the



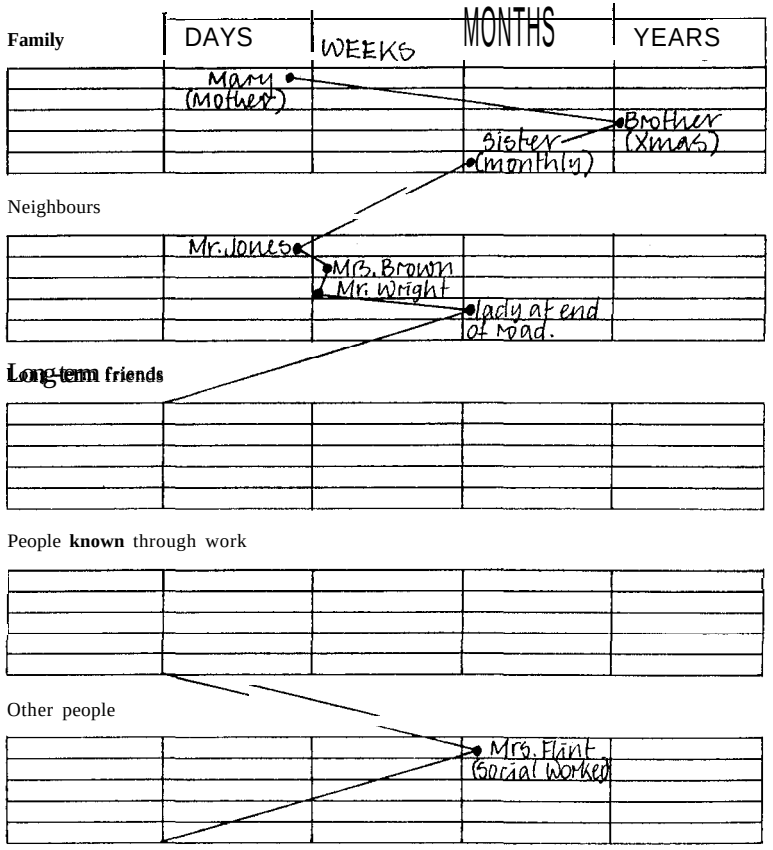
individual develop a wide enough circle of friends and acquaintances that they do not depend so heavily on a few people.

This means that one of the issues to which staff must attend is the range of relationships available to each individual they serve. Example 10.2 shows a simple chart which can be used in staff training or as part of the individual programme planning process or in weekly staff meetings to identify everyone an individual knows in the five categories of family, neighbours, long-term friends, friends and acquaintances known through work and other friends and acquaintances. If staff complete this kind of chart for themselves before filling one in for an individual with whom they work, the contrast can be used to generate ideas about new opportunities the service may need to promote.

As well as helping to develop a wider circle of contacts, staff need to pay particular attention to the impression they give to the friends and acquaintances of the people they serve. There may be an understandable tendency for a member of staff working with several people to regard a visitor to one of them as another pair of hands and to leave the handicapped person unsupported during the visit. This makes it more difficult for the handicapped person and their friend to manage the visit and it also removes opportunities for the staff to develop a sufficiently open relationship with the visitor to deal with problems as they arise. This places the visitor in the position of having to ask - to interrupt what the member of staff seems to regard as their priority activity - if they want help or advice or reassurance. Facilitating a visit is a task like any other kind of help staff might provide; it needs to be included in the discussion when staff work out their responsibilities at the beginning of a shift and the staff member involved needs to treat a visit as at least as important an activity as housework tasks with the other people they serve.

**Example** *I0.2*

**Mapping individual social relationships**






A similar risk is that one person's friend is encouraged to become someone else's (a kind of rationing of scarce friendships). This denies the importance of individual relationships and is likely to impose too great a sense of duty on the friend.

Among those relationships which become relatively close and perhaps longer-lasting, two kinds will be particularly important. The first is a sexual relationship, where many of the ethical and philosophical issues about people with mental handicaps are seen as most challenging by staff, relatives and other friends. The issues involved have begun to be explored and there is a considerable body of practical expertise on which the agency can draw to train its staff.

The second special type of relationship is where a friend becomes a kind of advocate for the handicapped person, recognised by the service as being able to represent that individual's interests. There may be a conflict between the advocacy role and friendship, but the difficulties this poses may not be any greater than those caused when agencies try to find citizen advocates from scratch. At least some of the roles expected of advocates - stepping in to support an individual in times of trouble, providing a reference point with whom to discuss important personal issues, and attending stressful meetings together - are roles which other people expect from their friends more than from advocates (such as Union representatives or lawyers).

Inevitably, as an individual acquires a network of friends and acquaintances there will be problems. Given the added complication of needing staff to help act as intermediaries, many such problems will relate to how the friend and staff perceive each other, as well as changes in the relationship due solely to the friend and the individual handicapped person. Clearly some kinds of interpersonal style are more likely than others to make a relationship resilient enough to cope with occasional stresses: being able to discuss issues frankly before either party has made too great an investment in their own position; avoiding blaming the other person; and focusing

on the problem issue rather than permitting the whole relationship to come under threat, are all relevant strategies. But perhaps the most important point for staff helping someone with severe or profound mental handicap is the same sense of perspective they apply to their own social network. Relationships have a natural history and at any one time some can be expected to be withering while others grow in intensity and intimacy. Just as it is wrong to expect people to survive without any relationships, so it is wrong to expect them to maintain in good repair a single set of relationships. The members may change over time; it is the network which must survive.

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# 11. Quality Assurance

At first the development of the new service will be carried forward on a wave of enthusiasm. Because it is new it will command extra resources, time and energy; people will take a close interest in its progress and there will be the satisfaction of solving many new problems. The deprivation and neglect of the old service will stand in stark contrast to the aspirations of the new, and it will be easy to fire new staff with enthusiasm.

In most services, this enthusiasm gradually ebbs away and is not replaced. The people who thought through what the service should be like move on, to be replaced by people with a less clear picture of the service mission and a weaker commitment to its principles. The early optimism is tempered by experience of failure and compromise, and management attention shifts to new concerns. In day-to-day decision-making people come more and more to adopt solutions tried before, even if they come from the old service, so that innovation declines and the new model of care decays as its practices drift back towards those of the traditional service it was designed to replace.

No-one has much experience of how to counteract this decline. Typically, the problem is identified as one of falling standards and the common solution is for managers or outsiders to monitor performance against a checklist of issues. Since this depends on outsiders making special visits, monitoring tends to be relatively infrequent and the visits are too short to address all the relevant issues in depth. There is evidence that standards may improve during such visits but soon revert to normal levels afterwards. Under these conditions the monitoring style becomes one of exposing lapses and deficiencies, giving the whole enterprise a punitive flavour. The checklist itself may incorporate assumptions about the model of care which are quite inappropriate for community-based housing services; it may also be insensitive to the real



experiences of people receiving the services (which take time and much direct observation to encapsulate). If staff perceive some of the checklist items as inappropriate this, together with the short time the visiting team is present, will help undermine the credibility of the monitoring process.

The alternative proposed in this chapter recognises that outside monitoring has a role to play but also examines more closely the culture of the service - what it is that makes people concerned about the quality of the service they provide and, just as important, able to do something to improve or maintain it.

A central principle in this is that *the aim is to teach staff to respond to the needs and desires of the people they serve, rather than to the behaviour of managers.* It is all too easy for staff to learn to satisfy the manager's expectations without this having any impact on the quality of life of the people they serve, either because the expectations are not relevant or because they can be satisfied without changing the outcome for the people served. Shaping the operation of the service so that staff respond to the people served is especially important where, as in services for people with severe and profound mental handicaps, the consumer often cannot express their needs or wants for themselves.

The objective, then, is the creation of a climate of innovation and development, in which staff feel motivated to assess the quality of their service and to improve it. Four elements of service organisation need to be brought together to achieve this goal: clear leadership, so that staff get an unambiguous message about their task; regular staff meetings to establish the process of enquiry and innovation in the staff team; management practice consistent with achieving better services; and independent validation of the quality of life of the people served and the ability of the service to continue to meet their needs. These four elements are addressed in turn in the first half of this chapter.

Having dealt with creating an environment in which quality matters, the discussion then turns to the agenda of

issues which should concern those involved in developing staffed housing for mentally handicapped people. The remainder of the chapter is devoted to the kind of questions that need to be asked about quality-related issues, both in terms of identifying achievements in the quality of the lives led by the people served and in terms of maintaining the infrastructure of the service so that it stays resilient and able to cope with new demands. Where appropriate, suggestions are made for how these questions can be addressed by the four elements involved in the quality assurance process.

## Establishing the process of enquiry and innovation

### *Leadership*

The project organisers have a responsibility to ensure that the service organisation itself gives unequivocal guidance to staff on two key issues. The first is a clear statement of the principles on which the service should be based and the objectives it should achieve for people with mental handicaps, so that staff have a clear reference point for the work they do. Just as important is saying clearly that staff are expected to discuss openly and constructively the ways in which these objectives can be better achieved without needing to fear a defensive or punitive response from management.

Saying these things clearly in formal policy is an important discipline for managers and protection for staff; but the explicit goals of organisations are often at variance with other (often less worthy) aims. If the organisers show by their behaviour that they are more concerned about staff overtime or maintaining tidiness than about quality of life, staff will learn to give these issues priority. Effective leadership means not only that the formal policy backs quality assurance but that in all the many influences on how staff perceive their job the



organisation places service quality above administration or conformity.

Since compromise will often be forced on staff because of insufficient resources or the unavoidable demands of administrative procedure, it is important to adopt the kind of approach described in Chapter 2 - making compromises knowing what their effects are, knowing that the best has been done at the time and knowing how a better result can be achieved next time. Periodic reviews (such as a one-day workshop each year) of their own performance by the project organisers or service managers themselves, matching what they claim are their objectives and principles with what the agency actually does, are needed to identify inconsistencies or areas where further progress can now be made. This can also be combined with an independent review designed to provide a fresh look at the achievements of the service.

There is another, more direct sense in which leadership is vital in maintaining good quality services. This is the extent to which staff can look to project organisers or specialist professional staff for models of good practice. This kind of leadership is scarce; it does not seem to have been readily generated by traditional services or by professional training, so that middle managers or specialists who can demonstrate to staff a better way of working with an individual are few and far between. Thus, once the principles and objectives are accepted, staff at the front-line often have to rely heavily on their own imagination and persistence to achieve new goals.

Since showing people how to do things better is a relatively simple way of improving performance, service agencies will increasingly want to fund training that turns out professional specialists with demonstrably more practical skills than relatively inexperienced care staff, and to develop personnel policies so as to retain the expertise they build in their existing staff.

*Using Staff Meetings*

Teamwork by staff is essential if the people served are to experience consistent and coordinated help in their day-to-day lives. Relying on individual staff responding to professional codes of conduct encourages idiosyncratic performance and helps generate conflict. The opportunity for staff to work out what they are going to do together is probably the single most important contribution to developing a good quality service.

The primary need is for a regular meeting of everyone to review progress and plan ahead. Experience in existing services suggests that a weekly meeting of from two to two-and-a-half hours, arranged so that almost all staff can attend, is needed. This meeting includes a fixed agenda of practical issues (progress in various kinds of intervention, coordination of plans etc.) and a time devoted to a wider-ranging discussion about how the service is doing and how it could be improved. This weekly meeting is the major focus of quality assurance processes and is discussed at length below.

In some services the weekly meeting includes the people served, for the same sort of reasons given in relation to IPP meetings. Similarly, it might be thought that managers or the project organisers or families or advocates of people served should attend. From the point of view of teambuilding, the criterion is that people feel free to talk candidly at the meeting and that they feel they are responsible for coming up with the good ideas the meeting generates. Another forum is appropriate if the purpose is to *account* for the standard of service being offered.

*Making Quality Matter*

The review of how well the service is doing and how it can be improved has to take place against a background of openly available and verifiable evidence about the quality of the service. There is value in simply using a list



of issues as an agenda to stimulate discussion, but it is important to have routinely collected information about service performance, both because it is easy to collectively delude oneselves about what is really happening and because this evidence is important for defending the service from outside pressures.

Since, by and large, people will not want to keep records unless they need them to do their job it is necessary to work out how useful information can be generated as a by-product of helping mentally handicapped people rather than as a special response to managerial pressure. Similarly, anyone faced with authoritative demands to achieve certain outcomes is likely to adjust the records they keep in the desired direction, so it is important that the focus of attention is always primarily on achievements for the people served (such as what they can do) rather than on process measures (an impressively high number of teaching sessions recorded). **A** range of suggestions is given later in this chapter for the kind of topics to be addressed and the information to be drawn upon in discussing them.

Even where people generate useful information about quality they may be satisfied with poor levels of achievement, either because of their own low expectations or because they have given up trying to change things. Therefore the service needs not only to maintain its openness to new ideas but also to encourage the involvement of people who want to improve things. There is some evidence that, unlike industrial workers, most staff working with people with mental handicaps derive part of their job satisfaction from the quality of their work. Instead of squandering this resource by teaching people that nothing they do makes any difference, the service agency should be fostering commitment by rewarding attempts to make progress.

Although staff need to have an ambitious vision of the future, it is also important to keep a practical, developmental perspective in staff meetings. If people feel that their worth is only measured against a high ideal they will become less willing to talk candidly about the

deficiencies of current performance. Instead, the team leader needs to impose a paradigm of accepting where the team is up to and looking forward to step-by-step improvement. This can be reflected in the kinds of issues focused upon as short-term goals. In the beginning, staff may need to focus on opportunities for the people they serve to participate in everyday household tasks; later, as widespread participation becomes routine, they will need to set their sights higher in terms of less mundane experiences or higher levels of choice and control.

The use of a participative approach to management (giving people a wider span of control over the things that matter, such as duty rotas or transfer between budget headings, so they can give effect to their own ideas for achieving goals they have set themselves) can create a sense of collective commitment among staff and a dynamic for steadily moving on to new goals. It remains essential to safeguard the direction in which the service is developed by staff. Partly this is provided by the operational policy of the service, which articulates clear objectives and principles against which new ideas can be judged; but it is also important that staff should themselves develop a shared vision of the mission of the service and its role in the lives of the people who depend on it.

*Developing a Shared Vision*

People who start new things are often driven by the tension between how things are and how they might be. They have some sort of vision of the kind of lives people with mental handicaps could live if services matched the very best examples of work in any particular area and if they were properly resourced. Part of the creation of a climate of concern with quality is constructing this kind of vision shared among the people involved in the service.

New ideas can come partly from looking at good practice elsewhere, but probably the major source of inspiration in developing a shared vision will be the



imagination of participants in the discussion as they talk through the aims and philosophy of the service. Athough this vision needs to be receptive to new ideas, it is also important that this shared vision is, in a sense, owned by the people in the service rather than seen as imposed from outside. People are more likely to respond to goals they have participated in setting. This means that enough time needs to be provided for this discussion to develop among staff. Part of the job of the project organisers is to facilitate the staff working as a group in dealing with these issues, both by protecting the time it requires and by encouraging and defending the process.

The role of the team leader is crucial in group discussion by staff. They will have to encourage staff discussing an issue to turn statements of problems (often expressed in hopeless or global terms) into goals, to formulate ideas about a range of solutions needed to achieve the goal and to agree collectively on a sensible course of action. They must therefore act as a facilitator, but they must also be ready to shape the discussion authoritatively. This may mean correcting inaccurate or punitive comments to avoid blaming individuals, or it may involve coming up with a possible solution when everyone else has exhausted the possibilities. If the team leader does not know at the start of the meeting what kind of solution they would adopt if the meeting does not come up with a better one, they are inadequately prepared. There is a difference between adopting a facilitative (as opposed to an authoritarian) model and simply not knowing what to do.

*Marragernerrt*

The point has already been made that managers need to make their behaviour consistent with what they claim are the aims of the service. They also have an important facilitative role for the staff team.

Staff have to experience success when they suggest changes, if they are to find that they can effect

improvements in the service they offer. This means that managers have to follow the lead given by their staff in selecting priorities and working out interventions to improve the service. Of course there are constraints on this process: managers also have to lead by giving a clear direction in terms of the aims of the service and by firmly closing off dptions which do not improve service quality. But if managers ignore or refuse enough proposals, or if success for the staff is re-interpreted as failure by managers because they are using different criteria or because rules on a hidden agenda are broken, then busy staff will stop wasting their time making proposals to change anything. For the manager, this means living with some uncertainty and, perhaps, accepting modest goals to establish the process of goal-setting and self-monitoring so that these can bear fruit in more ambitious goals in the longer term.

The management role also includes defending the staffed housing service from explicit pressures which would subvert it. Typically, a decision made elsewhere in the agency or even outside the agency by people entirely unconcerned with service delivery has a potentially serious impact on the ability of the staff to deliver a good service. Examples of this kind of problem are:

1. uprating fire precautions guidance for hospitals or hostels, so that obtrusive additional wiring and sensors are festooned about an ordinary house
2. the agency deciding to use pre-cooked food in all its service establishments to save money
3. ruling that all personal income of the people served which is unspent by a certain day each week is returned to the agency headquarters for banking, because some staff in another setting had been embezzling funds.

In these cases it is likely that the decisions were made for reasons valid in other circumstances (such as large institutions) and it is the managers' job to take



responsibility for not complying (where compliance would adversely affect the people served) while sorting out at senior level an appropriate waiver or alternative suitable for a staffed housing service. If the managers are not ready to shoulder this burden, they demonstrate to their staff that they are not particularly committed to the principles they espouse and that they are not prepared to back their staff in a dispute between quality and bureaucracy. Under these conditions, staff cannot feel secure that they have management backing for progressive policies, including policies where a measured degree of risk is involved. They are therefore likely to revert to traditional practices. Part of the manager's role in defending innovation is taking some of the responsibility for innovation and uncertainty upon themselves.

Over-generalisation from isolated instances can also cause new rules to be invented. Examples are that one person from one staffed flat loses their way on one occasion walking to their work-experience placement and someone proposes that no-one living in staffed housing ever be allowed out unaccompanied by staff; or that since fourteen windows have been broken in one house plastic windows will be installed in perpetuity in all staffed houses; or that vinyl flooring will be used because a carpet once got badly soiled.

This kind of example seems to be a common cause of systematically denuding the environment in which people with mental handicaps live. The process of taking away opportunities or furnishings or beauty appears much more powerful than the ability of the people served to earn back these things. Over a period of time, sometimes so long that no individual member of staff realises the full extent of deterioration, the environment is reduced to the lowest common denominator. Here the role of managers is not just to accept responsibility for resisting these rules but to campaign in favour of the principle that the people served do not have to earn decent treatment (that if damage is done or accidents occur the question is how staff can take reasonable steps to promote a successful outcome in future), and that services are tailored to

individuals and - not to stereotyped generalisations of handicapped people.

This leads to the final requirement of managers in a staffed housing service. Managers represent their service to the rest of the organisation, and they bear the responsibility of presenting a coherent account of what the service is trying to do and the extent to which it is achieving worthwhile goals. This means continuing to maintain the coalition of support created at the beginning to get the project off the ground. If the coalition is allowed to decay, the service will become less able to cope with threats or problems and more likely to have its central purpose subverted, even though the effects may not be immediately seen in the quality of care. One possible way in which the progress of the service can be publicly verified and established is in the production of some kind of annual report, in which the achievements of the year are catalogued and the issues which continue to challenge the service are acknowledged. Such a report can set the occasion for senior staff in each agency, or members of public authorities, to confirm the direction in which the service is going or face up to any issues on which they want to qualify their support.

In practical terms, this facilitative style of management is likely to require a committed group of managers working across traditional disciplinary and organisational boundaries, with a strong, coherent vision of future services. Such a group almost certainly existed to set up staffed housing in the beginning. If this group is allowed or made to disband once the service is set up, leadership and management will be dispersed among the elements of the formal structure of the organisation and correspondingly weakened. The project team therefore needs to be maintained, its emphasis shifting from development to enhancement of the capacity of the service to meet individual needs and to resist decay and disruption.



*Independent Review*

The purpose of independent review is to validate the decisions being made within the service - to show that the aims are appropriate, the achievements claimed are true and the fabric of the service is in good condition. Independent review can be done by a group including peers of the staff, people with mental handicaps using the service, their advocates or family members, or by people using a relevant assessment framework like Program Analysis of Service Settings or its derivatives. There may be special educational or network-building value in using people with some service connection (like family members or peers of the staff) for some kinds of review, but there is a special value in bringing in a group from outside in that it ensures a new set of eyes to look at the operation of the service.

The second virtue of independent review is that it provides an opportunity to measure the achievements of the service more accurately. It is most unlikely, for example, that staff will want to or be able to collect observational data on participation in activity or on the skilled delivery of teaching by staff as a routine part of their job. Periodically however, extra people can be brought in to collect this kind of data both as part of a staff training exercise and as a way of checking that the proxy measures used by staff from week to week do still have some merit. Even though most people find the idea of someone else watching them doing their job difficult to accept, observation remains the only way of obtaining independent, quantifiable, verifiable evidence about what really happens.

The other element of independent review is the use of citizen advocates or other authorised representatives to assess the service as if they were the handicapped person served. This provides the benefit that the advocate knows the individual and their circumstances quite well and so can judge the reasonableness of the service provision, but it has the potential disadvantage that this shared

knowledge will make it harder to ask new questions or spark new aspirations.

## Targeting Issues of Importance

The remainder of this chapter deals with specific issues which need to be addressed in the quality assurance process. In the spirit of the participative management approach referred to above, the emphasis is much more on the dimensions to be attended to than on the levels to be achieved, in the belief that staff are more likely to develop a quality-conscious culture if they start from their own current performance and raise their sights as they make progress. Relevant sections of this book suggest kinds of evidence staff can routinely collect to use as the basis for discussion in their staff meetings; for other issues the need is more that the item should occasionally appear on the staff meeting agenda rather than that it should be tracked week-by-week. In either case, information routinely generated about the way the service works is probably only one source. Responding to the evidence rather than opinion or guesswork is an important discipline, but it is also important to lift the gaze above whatever checklists and indices are used to take a broader view of the important issues and how they might be addressed.

As well as being discussed by the staff at their weekly meeting, some of these issues will also arise in any individual programme planning process, where the information gathered by staff can be used to inform longer-range planning. A third use of this list of specific issues is in compiling an annual report on the service, where the results of an independent review might be combined with information generated by staff to provide an authoritative account of how well the service is achieving its aims.



### *The Lifestyle of the People Served*

The 'five essential accomplishments' of services for people with mental handicaps (see Chapter 1) can be used as the framework for judging the quality of the lifestyle experienced by the people served.

Discussion of the extent to which the person served is present in the mainstream of arrangements for living, working and leisure and the level and variety of ***actrvities*** in which they participate can start from the evidence available in the participation index described in Chapter 9. This gives enough detail to distinguish the individual activities instead of global descriptions like 'housework' or 'trip out', so that the extent to which each person actually directs and carries out the activity can be readily reviewed. The information about contacts with other people can be used to inform discussion of how much the individual spends as part of a group, how much time they spend with other people labelled as handicapped and to what extent they actually meet other people when they go shopping or use other community facilities.

The participation index also has something to contribute when reviewing the personal growth and development of the individual in competence; the kinds of activities undertaken and the extent to which the person actually carries them out on their own are evidence of their current level of expertise. The discussion can focus not only on how this is changing but also on what staff can do to help the individual break into new areas of competence. The other usual source of information about personal development is the results of courses or programmes of special teaching, like the opportunity plans or the precision teaching approaches described in Chapter 9, or formal courses of study in a college or evening class. Some care needs to be exercised, however, before using the number of goals achieved in a teaching programme as any kind of useful evidence. Without some verification that the goals set are not trivial, and that the learning has been followed through to make a real

difference to the person's daily life, it is possible to get impressively large numbers which mean very little.

One special aspect of competence is the extent to which the individual is gaining self-control over their own behaviour, so that there is less chance of it seeming inappropriate or problematic. In a high-quality service, problems serious enough to cause concern will have been tackled by making special arrangements for staff action, which will include collecting evidence that acceptable management of persistent problems is achieved from day to day and that progress is made in helping the person get what they want without using the behaviour others find so challenging. Since 'problem behaviour' is almost always a social problem between the handicapped person and those who live and work with them, independent review of progress can be particularly helpful - not so much to check that what staff say has happened has really happened, but to provide a new pair of eyes on what is defined as the problem and what are reasonable objectives. Independent review also offers the important opportunity to highlight issues which may be important to the individual but which staff have become tolerant or immune to; much minor self-injury and self-stimulation, for example, ceases to be noticed by staff as they get to know the person, even though it may still influence strongly that individual's ability to join in other activities, or how they are seen by people outside the home.

The staff team also needs to review the *choice* the person has in their life. The participation index indicates when people join in and when they refuse, so that important activities which are not being made sufficiently attractive can be identified. It could also be used as the starting-point to discuss which activities people are in control of. This discussion needs to range from control over everyday matters like what to do, when to do it, and how to do it, to much bigger issues like how the organisation of activities, the deployment of staff, the way the service works, the way it helps to expand the range of choice and the extent of control of the people with severe and profound mental handicaps served.



In Chapter 10 a simple social network map (Example 10.2) is given as an example of the kind of tool staff can use to monitor the range and variety of friendships and other *relationships* possessed by each person they serve. It is suggested that the map generated for a severely or profoundly mentally handicapped person in the staffed housing service could be compared with one generated by staff or a friend or relative as a normative comparison. This kind of review could be done once or twice a year, either as part of the staff meeting or as part of the individual programme planning process.

Similarly, the perception of the individual by other people (the *respect* in which they are held) can be reviewed infrequently but systematically. This needs to take into account everything which helps project a particular image of the individual: the physical setting of the service; the kind of people it groups together, both as consumers and staff; the activities it enables people to undertake and the autonomy it enables them to exercise; the symbols and imagery the service projects through its corporate identity and the language it uses; and the appearance and possessions of the individual people served. Photographs and samples of text from reports or official documents can be used to stimulate discussion and reflection on what the service accomplishes and how it might be improved.

### *System Maintenance*

Although these five accomplishments can be used as an ultimate measure of the success of the service in terms of the outcomes it achieves for the people who use it, there is also a need to review the components of the service itself, so that gradual deterioration in standards can be noticed early on, before it is translated into effects on the people served.

Example 11.1 shows one possible breakdown of the service components which can be used to identify subject areas for occasional review, so that each area is discussed

*Example 11.1*

Service components

| | |
|---|---|
| Basic resources: | accommodation; staff deployment and scheduling; staff continuity |
| Staff helpfulness: | the frequency and type of staff interactions with the people they serve |
| The organisation of care: | individual programme planning, the daily timetable, teaching programmes and other individual programmes |
| Support: | the behaviour of service managers and professional advisers or specialists |



in some detail about once a year rather than being 'nodded through' in the staff meeting every week.

*Basic Resources: Accommodation*

There should be two processes at work in relation to the physical environment of each house or flat used by the staffed housing service; repair and renewal to make good the results of wear and tear, and innovation and improvement to reflect the continuing adaptation of the home to reflect the interests, experience and demands of the people who live there.

Given the deprived history of services for disabled people, there are often few forces militating towards renewal. Inadequate expenditure on maintenance, poor workmanship and long delays have become the norm. Instead of trying to remedy this at a stroke for the first staffed houses, it is better to adopt the approach of any ordinary householder: using local tradesman by individual arrangement, supervising their work closely on site and paying by results; or undertaking the repair without professional help (or in this case only with the help of the staff). Day-to-day upkeep is therefore established by never letting decline set in for long enough that people get used to it; and this requires devolved responsibility and authority.

Similarly, less frequent renewal (like decorating) is best done one room at a time rather than (the common practice in services) the whole place at once, even if tradesmen are used to do the job. This has the advantages that it causes less disruption, and individual preferences can be more easily accommodated because there is less pressure to save money by bulk purchase. Frequency of redecoration can be adjusted to reflect the need in different rooms, so the house will contain a range of styles and reflect changes in fashion and the cost will be distributed more evenly year by year.

Improvement and innovation is also an integral part of maintaining the fabric of the home and it is important

that people are enabled to continue to accumulate attractive furnishings and possessions so that the home more closely reflects personal taste and continues to present an attractive image to visitors. This also provides the opportunity to correct some of the compromises made during the project definition and planning stages.

In order to prompt the staff team to review the accommodation they provide, one person can periodically present the results of using a checklist like that in Example 11.2. This has a page for each room and one for the outside of the property. On one side of the page the reviewer notes the decorative state of the room, and the state of repair of the fittings (window-catches, etc), the furniture and furnishings and the electrical or plumbing equipment. On the reverse, the reviewer is invited to take a critical look at the room as a whole when judged against some of the criteria from Program Analysis of Service Systems (PASS): e.g. the elegance and beauty of the room, the absence of institutional features and the impression gained of the occupants from the decor.

### *Basic Resources: Staff Deployment and Scheduling*

Reviewing the way staff are allocated needs to be done often enough to keep pace with the changing needs of the people served. The first changes will often be in the transition from waking to sleeping-in night staff, but it may also be necessary to adjust the times when several staff first come on duty in the morning to enable someone to make an early start to get to work or make similar changes in the evening. If the service takes on the task of supporting people in work or equivalent alternatives to traditional day care, then the whole pattern of day staff deployment may need to be altered.

There are four key questions to ask about staff allocation:

1. What proportion of their time are staff actually working with the people who live in the house, as opposed to doing administration or other activities?



*Example 11.2*

Checklist **for** quality of accommodation: living room

Decor

Walls
Ceiling
Woodwork

Physical condition

| | |
|---|---|
| Floor | Plaster |
| Skirting | Architrave |
| Fireplace and mantel | |
| Radiators | Pipework |
| Door hinges | Door handles |
| Window hinges | Window latches |
| Windowsill | Glazing |
| Curtain track | Mirrors |

Furnishings

| | Damaged | Worn | Stained | Weakened |
|---|---|---|---|---|
| Sofa/armchairs | | | | |
| Side tables | | | | |
| Cupboards/shelves | | | | |
| Television/Stereo | | | | |
| Carpet | | | | |
| Curtains | | | | |
| Lampshades | | | | |

Electrical

| | |
|---|---|
| Safety of sockets | Safety of switches |
| Fuses correct | Plugs wired correctly |
| Flex condition | Secondary lighting |

Use the reverse side of the form to comment on the attractiveness of the room, the impression it creates of the people who live here and the extent to which it reflects their individual preferences and tastes.

2. Is there enough coverage at busy times that each person served can call upon someone for help when they need it?

3. Do the same staff always work with each other, so that there are separate cliques with their own ways of doing things?

4. What proportion of senior staff time is spent working alongside basic-grade staff with the people served?

These questions can be discussed using the current staff rota as a starting-point. If the staff team cannot work out from their own experience a sufficiently accurate estimate of time spent in particular ways, this could be the subject of a special exercise in which people keep notes of what they do. In practice, if there are problems or potential problems, the difficulty is more likely to be discussing them in the staff meeting than in agreeing what they are.

### *Basic Resources: Staff Continuity*

Staff turnover is inevitable. It is made worse by low pay, poor career prospects and the need to obtain formal qualifications. Periodic review is therefore needed to check that the staff group still meets the criteria set at the beginning of the project. Three questions to ask about continuity are:

1. Is the age, gender and ethnic distribution of the group as originally desired, or has it become skewed over successive staff changes?

2. How many staff have been trained in each of the elements of the original staff induction training?

3. Has the shared vision of the aim of the service been passed on successfully to new staff, or has it been watered-down and perverted?

One practical option to facilitate continuity is to allow appointment of staff to precede rather than follow



resignations, so that there is an overlap. This can provide a 'pool' of supernumerary staff for a number of staffed houses or flats in an area, so that staff can be released for training. Such a pool also provides greater flexibility in matching up a good staff team and helps during periods of staff shortage.

### *Staff Helpfulness*

The concern here is the skill of staff in structuring their interaction with the people they serve to be most helpful. The issues are, therefore, those identified in Chapter 9: the frequency of contact, the use of a hierarchy of antecedent help, the contingency of attention and the language used in the interaction.

In some services (some residential homes for 'maladjusted' children, for example, or some staffed housing services for people with severe and profound mental handicaps in the USA) these issues are tackled directly by having managers take observational measures of staff/client interaction routinely, using these as an everyday part of the management of the service. Many staff say that they would find this approach too intrusive and embarrassing.

Nevertheless observing how people interact in a systematic way is probably the only way in which clear and sufficiently accurate evidence can be obtained. In order to use this approach, it is likely to be necessary to set it up as a self-help training and monitoring exercise for staff, in which they watch or film each other working with the people they serve, they discuss the issues together in the staff meeting and they choose whether and which parts of any of the records get shown to other people. Everyone would take part and this kind of mutual feedback would be so regular and frequent that problems for someone on one occasion would be soon forgotten when they were seen to handle the situation better next time. The job-aids included in Chapter 7 can also be used on these occasions.

In all those organisational structures which staff use to help them facilitate achievement by the people they serve, there is the risk of decay. Paradoxically, the more staff are successful at using structures like individual programme planning, and the daily timetable or individual programmes, the more they can blend them in to the daily running of the home so that they are not noticed, the greater the likelihood that they will come to see them as unnecessary. They will need to refer to the handbooks and job-aids less often, they will find the methods imposed irksome and they will worry about the obtrusiveness of these interventions in what is supposed to be a home.

If staff then leave out the parts of the procedures they like least, or adapt them, there is unlikely to be any problem. Their expertise and experience will carry them through without apparent difficulty. It is hard, under these conditions, to argue that they should have stayed with the original procedures. But over time, as these skilled staff remove the elements of organisation that made them skilled, they render the service more and more vulnerable. When a new stress is suddenly placed on the system (a new member of staff is unable to help someone manage their temper or someone suddenly loses weight) they are much more likely to get into difficulties. Worse, they may invent new approaches which are unlikely to work or violate the principles on which the service is based.

Periodically, then, it makes sense to review how one of the systems (like individual programme planning or the precision-teaching model) is being used, and particularly to identify which parts of the approach have been allowed to fall into disuse, so that they can either be reinstated or deliberately modified after a discussion of the options.





It is also appropriate (if rare) to give managers, professional advisers and specialists feedback on their support to the staff team. Here the issues are those discussed above for the role of managers (the match between what they say they want and what their actions show they want, responding to a staff lead in a participative management model, defending the service from outside pressure and representing the service to the rest of the organisation). For specialist advisers and professionals particular importance is likely to be attached to their performance in training or guiding staff in the successful completion of difficult individual programmes.

One way of tackling this is to review issues which members of staff felt they would have liked more help with, identifying the help and thinking in some detail about how they would like it to be given and finding successful examples which can be used as a model. This list of problems successfully and less successfully dealt with, can then form the basis for a discussion with the group of managers, professionals and specialists in which staff ask how *they* should have reacted to get the kind of assistance they want. By retaining the definition of responsibility as theirs ("what should we have done to get the right kind of help?"), this discussion can be less threatening to managers who may themselves feel isolated and insecure.

## Conclusion

It is important not to characterise the aim of a new service as perfection or despair. The two most important qualities in the service are its capacity to *develop,* to take on new ideas and advance in pursuit of new visions of what might be possible, and its *resilience* at withstanding hindrance and set back on the way.

Given the desperate state of most services for people with severe and profound mental handicaps, it is

relatively easy to fire a group of managers and service staff with enthusiasm to build a new service based on new visions of the future and new knowledge about effective methods of helping people. Given this commitment, it is not easy to stop these people, to drag them down to safe levels of cynicism and surrender: but it can be done. It is done not by one or two set-backs or battles lost, but by the steady stream of actions telling people "this cannot be done: you are a fool to try" at every turn on the way.

This book is an attempt to spell out in some detail the decisions which have to be made in setting up a service to provide staffed housing for people with severe and profound mental handicaps - to give advance notice of important issues. As more and more staffed housing projects are set up, the body of experience so gained will itself provide a shield with which to resist the prevalent climate of disincentives. In doing so, some of the issues laboured over here will seem dated and obscure and new challenges will come to the fore.

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## Appendix

Actual duty rotas worked over a three-week period in a staffed house

The Team Leader worked occasional split shifts and overtime is shown where attendance at meetings with managers required it.

WEEK 1

| | | SUNDAY | MONDAY | TUESDAY | WEDNESDAY | THURSDAY | FRIDAY | SATURDAY |
|---|---|---|---|---|---|---|---|---|
| | Team Leader | | 9/4 | 7.30/5 | 9/6 | | 9/4.30 | 7.30/3 |
| | Deputy | 7/2.30 | 7.30/3 | | 2.30/10 | 2.30/10 | 2.30/10 | |
| | A | | 2.30/10 | 7.30/3 | 7.30/3 | | 2.30/10 | 2.30/10 |
| DAYS | B | 2.30/10 | 7/2.30 | | 2.30/10 | 2.30/10 | 7.30/3 | |
| | C | 7.30/3 | | 2.30/10 | 2.30/10 | 7/2.30 | | 2.30/10 |
| | D | | 2.30/10 | 7.30/3 | 10.30/1 | | 2.30/10 | 7.30/3 |
| | E | 10/8 ** | | 2.30/10 | 10.30/1 | 7.30/3 | | 7/12 |
| | F | ANNUAL LEAVE | | | | | | |
| | G* | 7.30/3 | | | 7.30/3 | | 7.30/3 | |
| | H* | 2.30/10 | | | 10.30/1 | | | |
| | A* | | | | 10/8 | | | 10/8 |
| NIGHTS | B* | | 10/8 | | | 10/8 | | |
| | C* | | | | ANNUAL LEAVE | | | |
| | 0* | | | 10/8 | | | 10/8 | |

* Half-time staff filling one duty between them ** Staff working the opposite shift (days or nights)

**WEEK II**

| | | SUNDAY | MNDAY | TUESDAY | WEDNESDAY | THURSDAY | FRIDAY | SATURDAY |
|---|---|---|---|---|---|---|---|---|
| | Team Leader | 2.30/10 | (7/1.30 (7.30/9.30 pm | 9/4 | 9/4 | 10/5.30 | 7.30/3 | |
| | Deputy | 7.30/3 | | 2.30/10 | 7.30/3 | 2.30/10 | 2.30/10 | 7.30/3 |
| | A | 2.30/10 | | 2.30/10 | 2.30/10 | 7/2.30 | | 2.30/10 |
| | S | | 2.30/10 | 7/2.30 | 10.30/1 | | 2.30/10 | 2.30/10 |
| CAYS | C | 2.30/10 | 7.30/3 | 7.30/3 | 2.30/10 | 7.30/3 | | |
| | D | ANNUAL LEAVE | | | | | | |
| | E | ANNUAL LEAVE | | | | | | |
| | F | 7.30/3 | | 2.30/10 | 7.30/3 | 2.30/10 | | 2.30/10 |
| | G* | | | | | | 7/2-30 | |
| | H | | 2.30/10 | | 7.30/3 | | 2.30/10 | 7.30/3 |
| | A | | | | 10/8 | | | 10/8 |
| NIMTS | B | 10/8 | | | 7.30/1.30** | 5/10** | | |
| | C | | | 10/8 | | | 10/8 | |
| | D | | 10/8 | | | 10/8 | | |

**WEEK III**

| | | SUNDAY | MONDAY | TUESDAY | WEDNESDAY | THURSDAY | FRIDAY | SATURDAY |
|---|---|---|---|---|---|---|---|---|
| | Team Leader | | 9/4.30 | 7.30/4 | 7.30/5.30 | 9/4.30 | | 9/4.30 |
| | Deputy | 7.30/3 | 2.30/10 | | 2.30/10 | 2.30/10 | 7/2.30 | |
| | A | 7.30/10 | 7/2.30 | | 2.30/10 | 2.30/10 | 2.30/10 | 7/2-30 |
| DAYS | B | 7.30/3 | | 2.30/10 | 7.30/3 | | 2.30/10 | 2.30/10 |
| | C | | 2.30/10 | 2.30/10 | 10.30/1 | 7.30/3 | | 2.30/10 |
| | D | ANNUAL LEAVE | | | | | | |
| | E | ANNUAL LEAVE | | | | | | |
| | F | 2.30/10 | 7.30/3 | | 7/2.30 | 7/2.30 | 7.30/3 | |
| | G* | | | 7.30/3 | | | 2.30/10 | 2.30/10 |
| | H* | 2.30/10 | | | | | | 7.30/3 |
| | A | | | 10/8 | | | | 10/8 |
| NIGHTS | B | | 10/8 | | | | 10/8 | |
| | C | 10/8 | | | | 10/8 | | |
| | D | | 9/2.30** | 5.30/10** | 10/8 | | | |

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